

# How is dementia diagnosed during the pandemic? By Tom Russ, Heather Wilkinson, Katie Gambier-Ross, Denise Munro, Rose Vincent and Lindsay Kinnaird

*Recipient of UKRI (Engineering and Physical Sciences Research Council) Agile Research and Innovation Response to COVID-19 Award to research the diagnosis of dementia in the post-COVID clinic*

Dementia is a major public health issue with an estimated 885,000 people with dementia in the UK. Most people with suspected dementia are seen at a memory clinic where they will be told their diagnosis, however during the COVID-19 pandemic most memory clinics switched to remote consultations (often by telephone or video-call) to continue to meet the needs of patients while attending to infection control concerns. Although this rapid change to remote consultation was essential to minimise the risk of spreading the virus, little attention has been given to our three main areas of concern: the potential practical, ethical, and emotional impacts of this change.

1. Practical impact. Is it possible is it to assess someone remotely and are there risks of misdiagnosis?
2. Emotional impact. What is the impact of being told that you have dementia over the telephone, particularly at a time of social distancing from friends and family?
3. Ethical considerations. Is it ethical to deliver a dementia diagnosis in an uncontrolled environment?

While sharing the diagnosis is recognised as important, it has to be done sensitively and with appropriate support immediately afterwards and on an ongoing basis. Remote assessment may require use of technology that patients are not familiar with and careful consideration needs to be given as to how the access is made as simple as possible.” (Underwood et al., 2020, Providing memory assessment services during COVID-19. DOI:10.1080/13607863.2020.1830946).

There is a significant lack of clarity around how the person with dementia experiences the process of dementia assessment and diagnosis. Much literature on remote diagnosis is focussed on rural areas with little attention being paid to the lived experience of people living with dementia who are underrepresented in research, particularly in relation to receiving a diagnosis. A better understanding of this experience would enable personalised support to be delivered to people living with dementia during the remote diagnosis process. It would also empower professionals to deliver a diagnosis in a better-informed and empathetic manner.

Through understanding these experiences, the dementia diagnosis project will allow people with dementia to be better supported during the diagnosis process. Continuing to deliver diagnosis is vital to access appropriate care and support. Delivering diagnosis by telephone or video-call may be the “new normal” even post-pandemic, as we are predicting a shift toward remote and digital services.

## **Methodology**

We will recruit people who have had appointments at memory clinics since the beginning of the first UK lockdown and staff from across the UK, making contact through existing professional networks as well as more broadly through social media. We plan to recruit approx. 30 people who have experienced receiving diagnosis remotely and approx. 30 members of staff with experiences of delivering remote

diagnoses.

In order to foreground the experiences of people with dementia, we will draw on participatory approaches. We have established a PPI group of people with personal experience of dementia who will guide the research team. We will thematically analyse the interviews in consultation with PPI group and these will be used to inform an Online National Forum.

This Online National Forum will take place in phase two of the project and will bring together a wider range of stakeholders including people with personal experience of dementia, professionals and people working in dementia fields in an online consultation. The findings from the interviews will be presented at this event and discussions held to allow the participants to contribute to the outputs of the research project.

The online methodology used here means that the usual geographical limitations to implementing a project do not apply. We will be able to recruit people with dementia and memory clinic staff from across the UK, making our findings useful to a wider audience.

### **Timeline and Impact**

The project began in spring 2021 and is expected to run for 12 months. We will have several outputs for the research to share the learning as widely as possible. This includes clinical guidelines for practitioners, a briefing paper for policy makers, academic papers to develop the evidence and a short animated film and podcasts targeted at a wider audience. These outputs will also be shared with the people who have contributed to the research through being a member of the PPI group, taking part in the online national forum or being interviewed for the study, as well as being distributed more widely.

## **Team**

*Tom Russ (PI) is an NHS Consultant Psychiatrist in old age psychiatry who works in a memory clinic in Edinburgh. He has experienced the change in services first hand and ' to a limited extent ' seen how people with suspected dementia have been affected. He is Director of the Alzheimer Scotland Dementia Research Centre (ASDRC) at the University of Edinburgh and Chief Investigator of the Lothian Birth Cohort studies. He is an experienced clinical academic with extensive experience of NHS clinical services and of research recruitment, assessment of capacity, and consent.*

*Heather Wilkinson (Co-I) is Professor of Dementia Participation and Practice and has worked for many years on research that intersects the methodological and ethical challenges of involving people with dementia in research, practice, and policy. She is a founder member of the Scottish Dementia Working Group, Director of the Edinburgh Centre for Research on the Experience of Dementia (ECRED), and Co-Director of the new Advanced Care Research Centre at the University of Edinburgh.*

*Katie Gambier-Ross is nearing completion of her PhD with ECRED. She is experienced in using innovative qualitative methodologies to understand the lived experience for people living with dementia. Katie recently worked on a project providing psychological support via a mobile application to persons living with dementia and their care partners during the COVID-19 pandemic.*

*Denise Munro is the administrative secretary for the ASDRC and is nearing completion of an MSc in Science Communication and Public Engagement at the University of Edinburgh. Having also worked as a research assistant, and with dementia patients in long term care, she has valuable expertise to contribute to the PPI aspect of this project, dissemination of results, as well as her essential administrative assistance.*

*Rose Vincent is an intern on the project and a PhD student in ECRED and the ASDRC. Her research is exploring volunteering in the context of young onset dementia and will address inequalities in access to volunteering. She is particularly interested in developing our understanding of how we can co-produce research with people living with dementia.*

*Lindsay Kinnaird is a Research Assistant on the project.*

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## **COVID-19 and Caregivers of children with Intellectual Disabilities (ID) across the UK, by Karri Gillespie-Smith**

Caregivers of children with intellectual disabilities (ID) are more vulnerable to mental health difficulties when compared to carers of typically developing (TD) children. Intellectual disabilities are characterised by adaptive skill deficits, which can be associated with challenging behaviours (i.e. verbal and/or physical aggression, self-injury, disturbed sleep, and destructive tendencies).

Challenging behaviours should not be viewed negatively since they indicate levels of severe mental stress and distress reactions in those with intellectual disabilities. These behaviours are exacerbated by disruption to day-to-day routines (adaptive functioning), or restrictions on enjoyed activities and are conditional on the level of disability. Therefore, the COVID-19 pandemic and lockdown arrangements are likely to have triggered or exacerbated these factors.

It is important to examine how lockdown restrictions to education, respite and support services (all factors that are known to reduce caregiver stress) will impact both the carer coping strategies and children's challenging behaviours. Indeed, there has been evidence showing an increase in requests for psychotropic medication across Intellectual Disability services to manage children's challenging behaviour during the pandemic. This may indicate changes in the child behaviours or caregivers' perceptions of coping. It is therefore, crucial to understand the impact of the COVID-19 restrictions on both children's challenging behaviours and caregivers' coping strategies.

We invited caregivers to complete an online survey that recorded demographic data, as well as questionnaire data measuring children's challenging behaviours, caregiver coping strategies and caregiver psychological distress. We also invited the parents to respond to open ended questions.

Caregivers of children who were typically developing ( $n = 67$ ) and those who had intellectual disabilities ( $n = 43$ ) took part.

We looked at relationships between the data and also carried out a thematic analysis on the open text responses.

The results showed that levels of children's challenging behaviours were related to psychological distress (showing that both children's and parents stress levels were related). In addition to children's challenging behaviours, parental coping strategies (specifically denial and behavioural disengagement) posed an additional risk for caregiver psychological distress. This shows that how children and their caregivers responded to the stressful external events impacted caregiver mental health.

Responses from the open text questions on the survey were also analysed and some common themes emerged.

### *Theme 1. Confusing messages and guidance:*

Caregivers who had children with Intellectual Disabilities (ID) struggled to understand the media messages and communicate it to their children

*“I can say ‘no school, we need to stay safe’ but what exactly does that mean if you have no concept of a virus, of time, of school not being there, or if it will ever be there again.” (Caregiver 1).*

### *Theme 2. Loss of freedom:*

Children and carers experienced a loss of freedom in terms of not being able to do favourite things, activities—the loss of seeing friends and family, and for some individuals no longer being able to leave the house. Many of the respondents reported the negative impact of a loss of structure, routine and activities.

*“lack of routine, lack of going places, lack of activities he can do.”(Caregiver 2).*

### *Theme 3. Unsupported and Forgotten:*

Carers reported a sense of feeling unsupported and forgotten during the pandemic and lockdown, and highlighted a perceived absence of support from social, health and education services. There was a general feeling that they have been left on their own to meet complex educational, sensory-related, medical and social care needs:

*‘I was frustrated with restrictions on food purchases e.g. for restrictive diet I needed more than 3 of some items to get him fed for one week – I almost cried.’ (Caregiver3).*

and

*'a lack of support from specialist services. No check-ins.'*  
*(Caregiver 4).*

The results show that parental coping strategies pose an additional risk for psychological distress. Specifically high levels of denial (avoidance of the situation) and behavioural disengagement (reduction of efforts during difficult situations/giving up). in caregivers lead to higher levels of psychological distress. Since coping strategies can be changed, supporting caregivers in employing different and adaptive coping strategies has potential benefits throughout the transition out of covid-19 restrictions.

In addition the reduced social support, respite and clinical services were also detrimental to caregiver's mental health.

As we return to typical routines and normality both caregivers and their children with ID require targeted interventions and support to reduce the negative mental health outcomes associated with the COVID-19 lockdown. Lessons must be learned, support gaps need to be understood and our vulnerable groups require protection as society recovers.

*Karri Gillespie-Smith is a Developmental Psychologist interested in linking core social and cognitive constructs to mental health outcomes in typical and atypical development. She joined the Department of Clinical Psychology, University of Edinburgh as a lecturer in 2019. Please do contact her – [Karri.Gillespie-Smith@ed.ac.uk](mailto:Karri.Gillespie-Smith@ed.ac.uk) if you would like to hear more about this research or be involved.*

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# Exploring the experiences of homelessness during the pandemic, by Fiona Cuthill and Rosie Stenhouse

In March 2020, the people of the UK were confined to their homes as the Covid19 pandemic swept Europe and the question of, 'what do we do with the homeless?' loomed large in the policy corridors of the devolved governments of the UK. As Covid19 complicates existing health inequalities and exclusions from care, there was increasing concern that people with lived experience of homelessness already had high rates of infection and death. Reports from London were also indicating that people experiencing homelessness were thought to be 25 times more likely to die of Covid-19 than the general population. In addition, people experiencing homelessness were increasingly vulnerable to Covid-19 due to lack of ability to follow recommended public health measures of hand hygiene and social distancing, coupled with high rates of existing health problems.

In England, the 'Everyone In' strategy was introduced, directing all local authorities in England to provide self-contained accommodation to all street homeless people, and those living in accommodation that prevented social distancing and isolation (i.e. shared temporary assessment centres and shelters). The Scottish government built on existing work with the Homeless And Rough Sleeping Action Group (HARSAG) requiring local authorities to rapidly house those who were rough sleeping, accommodating them in city centre hotels.

Public Health departments were replete with panic at the high risk of potential spread among the homeless population, particularly those who were sleeping on the streets and in

hostels. Alarm bells were ringing about transmission pathways for people who could not isolate, and about death rates for those who already experience very poor health. Emergency meetings were held. Extra money was found. People with lived experience of homelessness and frontline homelessness workers found themselves in high-level zoom government meetings. Bureaucratic barriers were broken down. A solution was found. And so it came to be, that a plan was devised for people experiencing homelessness to be rapidly rehoused in tourist hotels in the city centre. By the end of March 2020, many cities in Scotland had repurposed their centrally located hotel rooms into individual accommodation to house people who had previously been sleeping on the streets or in homeless hostels.

Workers across the UK were challenged with the huge task of getting 'Everyone In' and providing support to vulnerable people who were likely to struggle with social distancing. This was an unprecedented move, ending rough sleeping in many parts of the UK almost overnight, placing homeless people in spaces (for example luxury hotels) where they would not normally be welcomed and changing the relations between government and the homeless sector as this highly marginalised sector became the focus of huge community effort. In Edinburgh, rapid work led by Edinburgh City Council and the NHS Lothian led to the creation of a Covid-19 hostel hub and new prescribing practices.

During this unique space in time, the Cyrenians Scotland began a project called 'Living With Covid', where frontline workers, people with lived experience of homelessness and managers documented their experiences. This was funded by a grant from the Lankelly Chase Foundation. They did this creatively through poems, songs, video interviews, Tweets and photos. This data was collected for 3 months from the end of March – June 2020 and then subsequently analysed by two researchers, Dr Rosie Stenhouse and Dr Fiona Cuthill, through the Centre

for Homelessness and Inclusion Health at the University of Edinburgh. In total, 17 participants submitted their data to the Living With Covid project. This data has now been analysed and a report ready for publication in the next two weeks. This is a participatory project and the research team met last week with 12 of the participants in the 'Living With Covid' project to discuss the findings, agree the recommendations and to select the songs, photos, Tweets, quotes and poems that will be used to curate a community showcase exhibition later this summer. The findings from all of this work uncovered a city turned upside down: people who had previously been sleeping on the streets were now in luxury city centre hotels; people who normally stay in luxury city centre hotels were confined to their homes; and, frontline workers who normally work in homelessness services were either working from home or had the run of the empty city streets. It was a triumph of 'solving rough sleeping' and the homelessness sector were understandably proud of what had been achieved.

*Because the city has opened up these hotels and other residential properties to those who experience homelessness we have, as a city, almost completely solved rough sleeping for the time being. ['Frontline' Worker C4].*

And so began a period of paradoxical freedom and containment in the city.

### **A City Turned Upside Down**

*Poem by Dr Rosie Stenhouse created from the findings of the Living With Covid study, March 2020*

Lockdown

City streets lie empty

No longer bustling with tourists and office workers

Buildings, like sentries, line the streets keeping watch over

this new order of things

The ever-present hum of traffic replaced by birdsong

broken only by the passing of a bus carrying key workers

Familiar, weathered faces, sitting at the top of the steps  
into Waverley Station

Or outside the stores on Princes Street

Hoping for the few coins that passers-by might give

Now gone

No furlough to support them

As the pandemic removes their income

A tree stands forlorn, its narrow trunk and sparse branches

No longer needed for protection

A rectangular patch of bare earth, grass long dead

the only clue to the previous occupier of this spot

persuaded to take shelter in a city hotel

Hotels whose foyers and bars would

Echo with the voices of those from far off places

Whose rooms are a luxury that comes at a price

Find themselves occupied by a population

Unwelcome in such spaces in normal times

Bureaucracy and competition removed

Facilitates partnership working and a sense of purpose

Repurposing services to keep people safe

Rapidly

Within 48 hours

Unheard of

Policy makers and CEOs sit alongside those with experience of homelessness

Occupying equal size squares on the screen

Zoom the leveller, enabling access

For new voices to be heard

In the spaces where decisions are made

Norms and rules disrupted

This city is upside down

The 'Living With Covid' project is an excellent example of the ways that the University of Edinburgh and the local community are working together to shine a light into the amazing work of the homelessness sector in our city during the Covid19 pandemic. We look forward to the full publication of our findings at the end of May 2020. For a copy of the report, please contact: [fiona.cuthill@ed.ac.uk](mailto:fiona.cuthill@ed.ac.uk)

*Dr Fiona Cuthill is a Senior Lecturer in Nursing in the School of Health in Social Science, University of Edinburgh. She has a particular research interest in homelessness and refugee health. Fiona is the Academic Director for the Centre for Homelessness and Inclusion Health, which is a collaboration between the University of Edinburgh and local partners in Scotland to improve the health and wellbeing of people who experience homelessness.*

*Dr Rosie Stenhouse is a Senior Lecturer in Nursing in the School of Health in Social Science, University of Edinburgh. She has expertise in qualitative methodologies, specifically*

*narrative methods, and conducting research with vulnerable populations. She is Associate Director of the Centre for Creative-Relational Inquiry.*

- Photo credit: Photo taken by a frontline worker in the homelessness sector for the Living With Covid project.

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## **The cultural map of Edinburgh, in conversation with Morgan Currie**

**I gather that your report entitled ‘Art In and Out of Lockdown’ is part of a larger project which was started before the pandemic. Would you please tell us about that project?**

Yes. This report is part of the Culture and Communities Mapping Project – we put on cultural mapping events and design digital maps to look at how cultural spaces and events relate to local communities. We’ve created a cultural map of Edinburgh that came together through participatory workshops we hosted in 2019 ([www.edinburghculturalmap.org](http://www.edinburghculturalmap.org)). We’ve also worked with the local arts organisation LeithLate to design a digital walking tour of murals and art studios in the Leith neighbourhood. And right now, we’re working with Festivals Edinburgh and the Fringe Festival on a digital map that puts Festival activity in relation to different neighbourhoods in Edinburgh. For us as researchers, the project generally explores how community mapping, data and online tools can help us reflect on Edinburgh’s cultural geography and steer the city in a more inclusive manner.

**In this report you ask how Edinburgh’s cultural institutions**

**are supporting local communities. First, what was your methodology for gathering data during the lockdown. Secondly, what were your main findings?**

For this report we approached local arts institutions, plus a few festivals and the Council's culture department, to talk about how they are adapting during the lockdown and with Covid restrictions. We conducted interviews with eight organisations in total – the decision over which ones to approach came out of our 2019 mapping workshops, which identified a handful of organisations that participants felt were key cultural hubs for local communities.

Our main findings are dealt with in six sections in the report: first, the creative ways these institutions pivoted, quickly, to support local communities during the lockdown – in some cases, offering vital resources, such as food and ipads for online learning and communication. Second, the sudden need to rethink buildings and live events in terms of safety restrictions, and the loss of spontaneous physical interactions. Third, the abrupt funding and staffing challenges that arose, including the emotional toll of fiscal uncertainty; some interviewed pointed out how the pandemic has exposed the more fundamental lack of investment in arts and culture in the UK. Fourth, the renewed concerns for diversity, equity and inclusion that came out in 2020, both because of what the Black Lives Matters movement has shown about the colonial legacy of many cultural institutions and public statues, but also because of the local disparities that the pandemic exposed. Fifth, people we spoke to talked about all the work they did to switch to digital programming and outreach, such as online workshops and online funding campaigns; a few pointed out that switching online has the potential to build audiences outside the city, but also creates new divides for those lacking connectivity. Finally, people talked about how this time period has created opportunities to make programs more sustainable and to rethink

the tourist-centric strategies of festivals and culture in Edinburgh, to focus more on local communities.

**'Equity, diversity and inclusion' was an interesting theme of the report. The recent discussion about the Black Lives Matter movement in Edinburgh makes this particularly relevant. Could you set out the results of your research in the field of empowering Edinburgh's ethnic communities during the pandemic?**

This research project itself did not do anything to empower Edinburgh's ethnic communities. We did talk to people about efforts in this regard:

The Council, for instance, announced a Diversity and Inclusion fund in February of 2020 of £100,000 to be dispersed to Black, Asian and minority ethnic artists and Edinburgh-based organisations. The grants range from £5000-20,0001.

Museums & Galleries Edinburgh (the department of City of Edinburgh Council which operates its cultural venues) has committed to eight priority actions in its developing anti-racism pledge, including comprehensive anti-racist training and ensuring Black and minority ethnic people are involved in their programming and exhibition designs (accessible here: <https://www.edinburghmuseums.org.uk/about/anti-racism-pledge>)

The National Trust is foregrounding the role that slavery and imperialism played in the history of its regal homes, in the project Colonial Countryside, which consults young black and minority ethnic children to understand the best way to communicate the past to touring audiences – including stories of slave-owners' illegitimate children who lived on the grounds, goods looted from the Empire, and furniture made with slave-labour.

We also did respond by creating a dataset for our cultural mapping marking the legacy of slavery and colonialism in the city – this is found in the data layer on our map called 'Edinburgh Slavery' and is based off of local research by Lisa



Williams and Uncover.Ed, among others. We also added a category to our cultural dataset that shows organisations run by or for BAME communities. The data in this category are based off of research from our cultural mapping events combined with data we received from the Council.

*Morgan Currie is Lecturer in data and society in Science, Technology and Innovation Studies at the University of Edinburgh. Her research and teaching interests focus on open and administrative data, algorithms in the welfare state, activists' data practices, civil society and democracy, social justice and the city, cultural mapping, and libraries of things. She is principal investigator of The Culture & Communities Mapping Project and co-lead the Digital Social Science Research Cluster at Centre for Data, Culture & Society.*

▪ Photo credit: Morgan Currie

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## **‘Social distancing’ in Latin America during the pandemic, by Rocio Nava, Alex Janus and Emily Adrion**

For more than a year, the world has been grappling with the first global pandemic of the 21<sup>st</sup> century. The rapid worldwide spread of the SARS-CoV-2 virus has led nations to implement a host of new policy measures to protect health, to strengthen health care systems, and to control within- and cross-border spread of the virus.

One particular set of measures that governments have used to control the pandemic within their borders is termed 'social distancing'. Social distancing includes a range of policies designed to control the spread of the virus by limiting the contact that individuals have with one another, which can include measures such as bans on large social gatherings, stay-at-home orders, school and workplace closures, limiting unnecessary travel within and across regions, amongst others. While these measures are critical in reducing transmission of the virus, there may be unintended consequences for individual health and wellbeing that result from imposed social isolation. It has become increasingly clear that social distancing has had important impacts at both the individual and societal level that need to be weighed carefully by health authorities prior to and throughout their implementation.

Globally, there has been wide variation in the nature, timing, duration, and enforcement of social distancing policies within and across countries. As researchers, we have been particularly interested in how these varying policy responses to Covid-19 have impacted the lived experience of individuals. These issues are particularly important to examine in Latin America (LATAM), a region which has not only exhibited a range of policy responses, but has also been particularly hard hit by the pandemic.

Over the past year, we have been involved in the design and dissemination of an online survey aimed at understanding experiences and inequalities in outcomes associated with COVID-19-related social distancing policies. Our online survey includes both multiple choice and open-ended questions on a range of subjects – including questions aimed at understanding loneliness and subjective wellbeing during the pandemic, as well as questions capturing respondents' views and perceptions regarding social distancing and social isolation policies. In this blog, we share our preliminary findings relating to the latter, and present results of a qualitative analysis of the

free-text answers our LATAM respondents provided to the following question: *What are your views regarding social distancing or self-isolation?*

Respondents from 32 countries in LATAM (Figure 1) provided us with information on how social distancing and the pandemic has affected their daily lives.



Figure 1. LATAM

respondents' self-reported country of residence

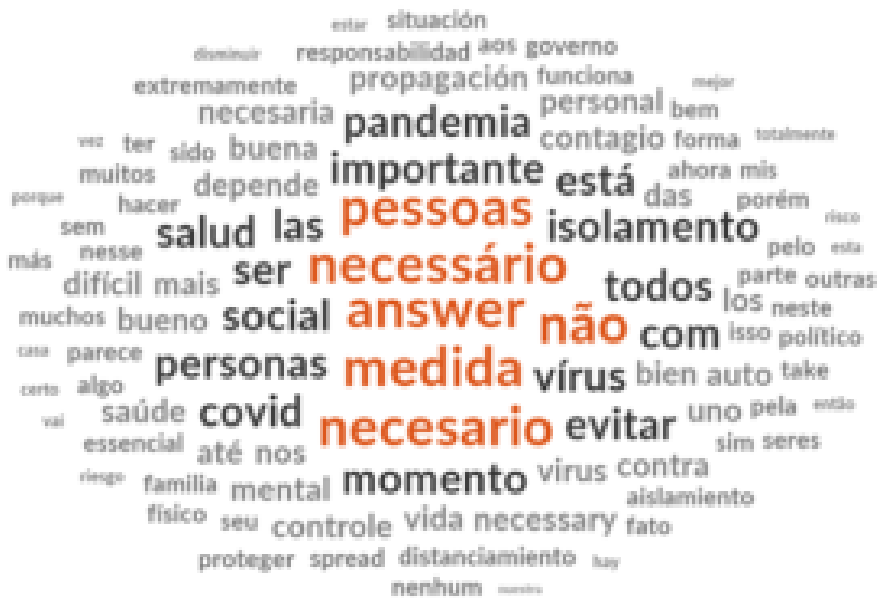
Below we present our preliminary findings from an analysis of 238 free-text responses capturing individuals' perceptions of social distancing policies. Respondents provided answers in Spanish, Portuguese, and, less commonly, English. Responses were analysed in their original language and translated into English below. NVivo was used to aid with qualitative analysis and manage datasets.

### Preliminary Findings

A majority of participants in our survey consider social

distancing to be “important” and “necessary” in terms of its contribution to stopping the spread of the virus (Figure 2).

Figure 2. The 500 most frequently used words in response to the question, “*What are your views regarding social distancing or self-isolation?*”



Note: Figure 2 (above) includes words from responses that were submitted in Spanish, Portuguese, and English, and excludes commonly occurring words (a, the, is, etc.) in each language.

However, despite the support for social distancing measures, there were also numerous mentions of the tolls that these measures were taking on individuals and societies. A hierarchy visualization was created using NVivo (Figure 3). This figure shows that, despite many reporting positive views of social distancing measures, the impact on mental health, the impact on personal income and national economies, and the sustainability of these policies were common concerns amongst respondents.

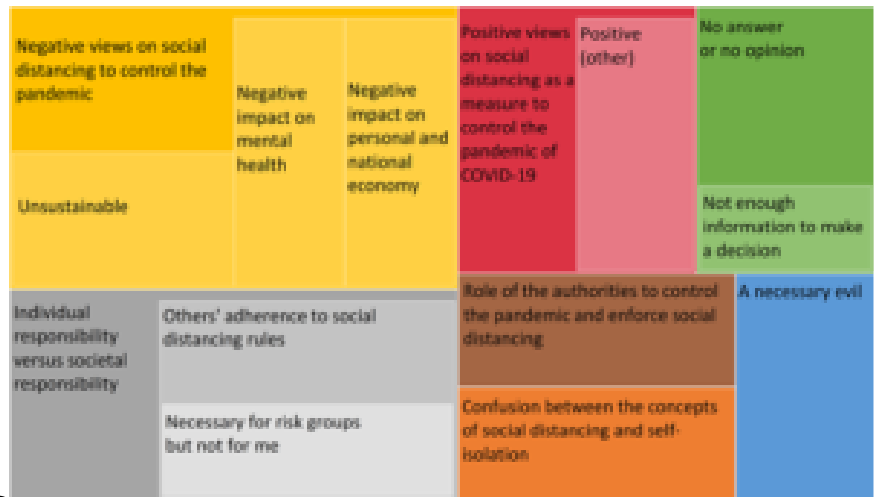


Figure 3. Key themes

Importantly, some participants, in describing how their job requirements did not enable home working, highlighted their views that social distancing is “a privilege”.

*“... que es un privilegio, la verdad no sé que otra solución hay para contener la pandemia”.*

*[... it is a privilege, I honestly do not know any other solution to contain the pandemic].*

*Male, 20, Mexico.*

Mental health seems to be a key concern regarding social distancing measures among our respondents. Some acknowledged this while raising the concept of social distancing as being “a necessary evil”, which could mean that many participants feel social distancing is necessary in the context of the pandemic, but they are also aware of the high costs associated with it, particularly in terms of the toll on their mental health.

*“Me parece bueno pero emocionalmente me afecta”.*  
*[I think it is good, but it affects me emotionally].*

*Female, 39, Chile.*

*“Necessario. Precisa ter muito equilibrio emocional”.*

*[Necessary. You need to have a lot of emotional balance.]*

*Male, 51, Brazil.*

Despite the hardships that respondents in LATAM described, there was a notable appreciation for the necessity of these measures, with some describing that they balance their individual needs and desires with the need for adherence to social distancing measures for the collective good:

*“Fundamental para o momento. É complicado, difícil, nada bom, mas muito importante pra controle e bem de todos.”*

*[Fundamental for the moment. It’s complicated, difficult, not good, but very important for the control and good of everyone.]*

*Male, 44, Brazil.*

## **Limitations**

While our sample is rich in terms of the range of participants from LATAM and the depth of qualitative and quantitative data we have from each, our sample is not a representative one. Of particular relevance here is the issue of selection bias. It is possible that the positive views of social-distancing as a containment measure against COVID-19 are over-represented in our sample, as those most concerned about COVID-19 control may have been more inclined to participate in our survey.

## **Conclusion**

Prior to the pandemic, income inequality, informal employment and underfunded healthcare systems meant many LATAM nations were vulnerable to inequities in health and wellbeing. As in much of the world, the pandemic has exacerbated existing policy challenges and introduced new pressures at the

individual and societal level; yet our findings suggest that our respondents remain largely supportive of social distancing policies. As the virus continues to spread through LATAM nations, it will be critical to continue to monitor the impacts on health and wellbeing.

*This work was supported by a Covid-19 Solidarity Grant from the Atlantic Institute.*

*Rocio Nava is a PhD Candidate in Health Sciences at the University of York. Alex Janus is a Lecturer in Quantitative Methods and Sociology at the University of Edinburgh. Emily Adrion is a Lecturer in Global Health Policy at the University of Edinburgh. The authors would like to acknowledge Talulah Hall, a recent MSc Global Health Policy graduate from University of Edinburgh, who contributed to the wider research that informed this blog.*

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## **Commissioning Art at the University: During and After Lockdown, by Liv Laumenech**

Through the engagement with the practices of commissioning, purchasing and displaying the work of artists, the University has amassed a collection of around 8,000 artworks spanning a period of almost two millennia.

The early stages of this collecting were closely linked with galvanising the institution's identity and status through the commissioning and collecting of portraits and busts of Professors and alumni. Over time, the University began to look to artworks as a means of decoration for the buildings and

campuses constructed as advancements happened in fields of study.

Today, the University of Edinburgh and CAHSS has a reputation for world-class research and high quality teaching; it is a place for experimentation, innovation and risk taking, with activities that challenge assumptions, inspire and make impact locally and globally. The Art Collection's vision and ambition for art at the University is no different.

Alongside displaying the collection across campus and lending to external venues, greater emphasis is now placed on the acquisition and use of artworks in the support and development of research and teaching. Commissioning art plays a significant part in this objective and offers up a real opportunity for internal and external collaboration at the University.

Commissioning is a practice that involves the engaging of an artist in the production of a new work of art. Historically this included paying artists to create statues, religious iconography or portraits of family members, but in the present day it covers an ever-expanding range of materials, processes and possibilities. During the Covid-19 pandemic, the Art Collection's commissioning has continued and included a series of commissions directly influenced by the tumultuous context.

### **The Lockdown Commissions**

In recognition of the challenges for artists produced by the pandemic, and with a desire to support individuals and respond rapidly to this major historical event, the Art Collection funded a series of three 'lockdown' commissions at the beginning of the 2020 lockdown in the UK.

Designed specifically to enable the production of new work during the period of enforced social distancing and limited movement, the commissions offered focused but flexible support, with artists invited to critically and personally



reflect on the period of social upheaval and change. The following three artists/groups were directly approached by the collection, and awarded £5,000.00 towards the production and acquisition of a new work.

***Daisy Lafarge b.1992***

*Five Tongues, 2020*

*Text work*

*Five Tongues is a text created by Lafarge in response to her experience researching and engaging with her immediate surrounds during lockdown, and particularly green alkanet (or Pentaglottis Sempervirens), a plant growing in her garden.*

*The plant's five tongues come from Greek (penta + glottis) and accordingly Lafarge divides the text into five parts or 'tongues' each exploring a different aspect of her journey of discovery. The text thoughtfully traverses botanical history, etymology, and the plants hosting of aphids and micro-organisms, to consider ideas of reciprocity, love, hearsay, and classification.*

The Art collection acquired the rights to the text, which was immediately embedded into undergraduate teaching in 2020/1. In addition Lafarge designed a limited print run, which was sold by the artist to raise funds for two charities. The text has also been featured in Daunt Book's 2021 anthology *In the Garden*.

This is the second work by Lafarge to enter the collection, after the moving image work, *Not for Gain*, was acquired from her 2016 ECA Degree show. Similarly to *Five Tongues*, Lafarge's approach to the research for *Not for Gain* was 'motivated by an attempt to foreground ecology as both subject and methodology.'

If you wish to read *Five Tongues*, please contact the art collection to get a digital copy of the text.



*Manual Labours (aka Jenny Richards and Sophie Hope)*

*The Global Staffroom 2020*

*Recordings of a live broadcast podcast series (14 episodes)*

*Manual Labours Manual #5 2021*

*A manual of research questions and projects*

*Manual Labours* is a research project exploring physical and emotional relationships to work, initiated by Jenny Richards and Sophie Hope. The project reconsiders current time-based structures of work (when does work start and end?) and reasserts the significance of the physical (manual) aspect of immaterial, affective and emotional labour.

During Lockdown *Manual Labours* were developing and delivering

*The Global Staffroom*, a live weekly podcast series of conversations and interviews with people about what it feels like to care, be cared for, not be able to care at work. Episodes covered topics directly relevant to the pandemic including architecture of home-work, racialised experiences of lockdown, emotional labour of care and health workers, social reproduction and remote working.

The Art Collection commission supported the production of *The Global Staffroom*, including the redesign of the Manual Labours podcast webpage. In addition, the funding has gone towards the compilation of *Manual #5* – a compendium of the research and questions developed from the podcast series – which will be available for use in teaching in 2021/2.

*ProjectWakaka* (aka Jennie Temple, Chris Walker, Rudy Walker and Alice Walker)

*All the Birds, 2020*

*Mixed media*

*all-the-birds* is a body of work made by !!Project!WAKAKA, a family of four based in Edinburgh. The family have been making work together on and off since 2010, but have renewed activity in light of lockdown and the Art Collection commission. This intense making and family isolation has resulted in homemade screen-prints, video work, drawings and writings as well as a vast amount of documentation of their conversations, one-off statements and reflections – both individually and as a family- over a four or five month period.

The title of the work comes from a project started in the beginnings of lockdown, which stemmed from a Daily Mail poster of common garden birds given to the family. Each member of the household picked a bird from the poster, drew and learned something about it and then printed it on the kitchen table using a homemade industrial drying process. This culminated in a final larger print of each printed bird collaged together.

The family has developed a website to organise the work that they are making, to keep track of developments, log thoughts and play. The final outcome is still in progress but, a selection of the material and surrounding documentation, likely to be combined into a publication, will join the Art Collection for use in teaching and research in 2021/2.

**To discuss using these lockdown commissions– or any other artworks in the Collection- in teaching and research please get in touch with the collection curatorial team: [is-crc@ed.ac.uk](mailto:is-crc@ed.ac.uk).**

*The University Art Collection is managed by the curatorial team consisting of the Art Collections Curator, Julie-Ann Delaney, and Assistant Curator, Liv Laumenech.*

### ***Other Information***

*The Art Collection is one of many University heritage collections managed by the Centre for Research Collections; a research lab for the humanities located in the University Main Library. Read about and search the Art Collection online here: <https://collections.ed.ac.uk/art>*

*If you are a student or staff member at the University, you can view the moving image artworks held in the Art Collection on [Mediahopper](https://media.ed.ac.uk/channel/Moving%2BImage%2BWorks/96102512).  
<https://media.ed.ac.uk/channel/Moving%2BImage%2BWorks/96102512>*

*Find out more about the Degree Show Purchase Prize on our [Google Arts & Culture Story](https://artsandculture.google.com/story/mQVR1auYkVafQ)  
<https://artsandculture.google.com/story/mQVR1auYkVafQ>*

### ***Looking to Commission?***

*The Art Collection can offer support and advice to those wishing to commission permanent and temporary art for university buildings, as an integrated part of research or*

*affiliated activity.*

*In 2019 the University Commissioning Guidelines were updated and rewritten by the Art Collection. To request a copy of the guidelines or speak about commissioning please get in touch with the curatorial team: [is-crc@ed.ac.uk](mailto:is-crc@ed.ac.uk)*

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# **How has covid-19 impacted the cultural sector?, by Dave O'Brien**

The pandemic has been disastrous in many ways, not least of which has been the tragic loss of life. There have been major upheavals across many sectors of economy and society, as individuals and communities have adapted to stop the spread of the virus. This blog post looks at the creative economy, presenting research from an AHRC funded project that aims to investigate the impact on audiences, institutions, and the workforce in the UK's cultural sector.

Pre-pandemic, the cultural sector was seen as a growing part of the economy, and was an important component of health and social policy agendas. This is to say nothing of the value and importance of arts and cultural engagement to people's everyday lives. Indeed, cultural participation, everyday creativity, and digital cultural consumption have played a major role in people's lockdown lives.

At the same time, we know from existing research that both the workforce and the audience for arts and culture are marked by extensive inequalities. As with much else associated with the

pandemic, the impact of Covid-19 has reflected these pre-existing inequalities.

We can see this clearly in the workforce. Using data from the Office for National Statistics' UK Labour Force Survey, the team I have been working with have charted both the overall impact on employment and hours worked in the cultural sector, alongside the uneven impact on different demographic groups. The story is complex. Some areas of the creative economy have sustained employment numbers, whilst others have seen catastrophic contractions in their workforce.

In the six months following the beginning of lockdown, the ONS LFS suggested there were 55,000 job losses (a 30% decline) in *music, performing and visual arts*, and significantly higher than average numbers leaving creative occupations as compared to previous years. Even where there were not high levels of job losses, for example in *film, TV, video, radio and photography* occupations, there were large reductions in working hours.

Government intervention has helped some areas of the creative economy. Our film and TV workers, for example, have covid-secure sets and studios, and the evidence from hours worked suggested the furlough scheme helped *museums, galleries, and libraries* occupations.

However, as high-profile campaigns have indicated, many cultural workers have faced grim conditions. This has been especially acute in *music, performing and visual arts*, partially as a result of the high levels of self-employed and freelancers in these occupations. At the end of 2019, ONS data indicated 88% of music, performing and visual arts occupations were self-employed, and freelancers, as a subset of the self-employed were 27% of the workforce. A high proportion of the 55,000 job losses were self-employed and freelance, and the latest data, covering the end of 2020 suggest the second lockdown saw further contractions in the number of workers.

In terms of demographics, we've used a combination of the LFS and the Longitudinal LFS to explore who is leaving creative jobs. More than a quarter (27%) of creative workers under the age of 25 left creative occupations after lockdown, compared with 14% of workers aged 25 and over. The U25s also saw greater reductions in the number of hours worked, as compared to the over 25s.

If age is a source of concern, then there are equal worries about those who have traditionally been excluded from the cultural workforce. In particular, ethnic minorities, women, and disabled people are all at risk of being marginalised, even from those areas of the creative economy that have not seen as severe contractions in numbers of jobs and hours worked.

At present, we are awaiting the data from the first part of 2021, in order to understand the impact of the third lockdown. Whilst there is welcome rhetoric about building back better, the impact on key parts of cultural production is likely to be a medium- to long-term issue, beyond the immediate problems our research is demonstrating.

Although cultural engagement seemed to be a key part of surviving lockdown, different social groups have seen differing patterns of consumption and participation. Again, these patterns reflect longstanding issues of inequality. The relationship between inequalities in production and consumption is complex; but even at the moment where culture seemed most essential, and the absence of attendance and 'live' events most keenly felt, the workforce may be under threat of becoming more unequal and more exclusive.

*Dave O'Brien is Chancellor's Fellow in Cultural and Creative Industries, based in the School of History of Art at the University of Edinburgh. He has published widely on cultural policy, urban regeneration, cultural work, public policy, social mobility, and cultural consumption. His most recent*

*book, co-authored with Drs Orian Brook and Mark Taylor, is Culture is bad for you: Inequality in the cultural and creative industries.*

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## **‘Everybody’s Always Here with Me!’: Pandemic Proximity and the Lockdown Family, by Hannah McNeilly and Koreen M. Reece**

*This article has been published in the Special Issue “COVID-19 and the Transformation of Intimacy” in Anthropology in Action 27(3):18-21 (December 2020).*

‘The main impact is that everybody’s always here with me! Including my ex-husband to be’, Jenny said with a wry chuckle. She was sitting on a grey sofa in her living room in central Scotland, though I could only see a corner of it via Skype. She explained that she and her husband were separating, but that he had had to delay moving out because of the lockdown. When the schools closed, just a week before our interview, they found themselves stuck in the house together with their two school-age children and very little space and time to be apart.

On 20 March 2020, nurseries and schools were closed across the United Kingdom in response to the growing threat of COVID-19. Families like Jenny’s were left scrambling to sort out care for their kids, bracing themselves for major changes in their working lives and trying to prepare their households to face a



disease no-one understood. Three days later, on 23 March, Prime Minister Boris Johnson declared a national lockdown and instructed the people of the United Kingdom to stay at home to stop the disease spreading between households.

On the same day the United Kingdom closed its schools, the World Health Organization advocated reframing the prevalent public health strategy of social distancing as 'physical distancing', in order to highlight the risk of social isolation (WHO 2020). 'Social distancing' nonetheless remains the term most used in the media and by the public to describe current public health measures, from working at home to ensuring a two-metre distance between members of different households. But what the catch-phrase misses is a crucial dimension of the lived experience of the pandemic: an unprecedented degree of inescapable *proximity* within households and the imperatives of finding new ways to manage space, time, selves and relationships.

In the first two weeks after school closures, we conducted semi-structured, remote interviews with ten mothers of children in nursery and in primary school. They were contacted through randomly selected council nurseries in central Scotland. We sought initial insight into the experiences of parents with young children and the ways they were navigating the sudden, drastic readjustments required by lockdown.

While important research has drawn attention to the threats of increased domestic violence under lockdown (Campbell 2020; Usher et al. 2020), our study considers subtler shifts in family dynamics in response to the new pressures of 'pandemic proximity'. It provides an early insight on how mothers handle the forced intimacies of family life under lockdown through the experimental management of space and time. The result is a more expansive understanding of the family in contemporary Scotland and a notion of intimacy characterised as much by distance and distinction as by proximity and mutuality.

## **Pandemic Proximity**

The closure of schools and workplaces, but also cafés, non-essential shops, and public gathering places, created a sudden, acute pressure on households to reconfigure their ways of living together. For the mothers we spoke to, being 'stuck home together' offered the welcome prospect of more time with their kids, but it also provoked unexpected anxieties. Natalie is a full-time lawyer and single mother living in a 'smallish' house with her three young children, who are aged between one and six years old:

*It's basically total chaos [child screams in the background] with the workload during the week. . . . I am just trying to do my job at home with the kids around which I think is actually just impossible. Or it's not possible to do it the same way, because as soon as you sit down to do anything, somebody gets hurt. . . . Yeah and you feel like you are just not good at doing a good job at any of them because, you know, firing out e-mails and then running away and just going from thing to thing. . .*

Natalie was perhaps the most overwhelmed of our respondents, but her concerns echoed those of other women we interviewed. Sonia, an NHS (National Health Service) surgeon with two primary school-age children, also anticipated school closures would create a 'nightmare' at home. She would continue working in the hospital during the lockdown and expected stressful times ahead: 'When the children are at school and I have time for myself, I just find that it is such a recharge space. . . . I am pretty anxious about not having that anymore and always having people here'.

If the space of the house did not feel overcrowded, time did. The sudden necessity of reorganising daily routines, and relationships in turn, was a particular source of unease. As Annie, who worked part-time in a grocery shop, put it: 'Now

the whole dynamic in the home has completely changed. Me and [my son] had a very strict routine, and now that's kind of gone out the window. I relied on that routine as my job, as being a mum, and now I feel this disconnect. Me and my partner don't know how to parent at the same time'.

From a public health perspective, households are key sites of potential contagion, as well as natural units of care. This assessment is based in part on the assumption that households are generally self-sufficient families, and that the two categories neatly overlap. Separating households was therefore a crucial tactic in preventing the spread of the virus and in providing in-built support for those who might fall ill at home.

Most of the mothers we interviewed worked to frame their homes as 'safe spaces' protected from the contaminated outside world, rather than as spaces of risk. Annie, for example, found it stressful to follow social-distancing rules at the grocery shop, but at home she felt safe:

*I feel safe when I'm at home, because my partner doesn't leave the house and neither does [my son]. Well, they do, they go out and go for walks . . . we make sure he doesn't touch anything metal, or anything that has been known to harbour the virus . . . He wears gloves and then, when they come in, we take the gloves off – when we're in the porch, we take them off. So, they are kind of clean, so when I am around them, I feel clean.*

Keeping the home a safe space, as Annie's description implies, involved reinforcing and sanitising its boundaries. Crossing those boundaries – stepping over the threshold – was risky and needed to be carefully managed. Nina, a university employee who lived in a flat with her husband and three-year-old son, described a new habit of putting her ear to the door before stepping outside to make sure that her neighbours were not in

the staircase.

At the same time, making the house a safe space highlighted and intensified its intimacies and the risks they presented. The women we spoke with were confined not only with children and spouses, but with partners from whom they were separating and could not be separated. And in some cases, the intensity of these intimacies took on a sharply physiological quality. Janet, who lived with her husband and their three sons, described the impracticability of self-isolation in case one of them developed symptoms. She could not physically separate from her breastfeeding baby, nor could she ensure the single shared bathroom would be wiped down after each use. Her family's physical proximity under lockdown, combined with the contagiousness of COVID-19, had morphed them into a unit of shared risk, akin to sharing a body; if one of them developed symptoms, all would have to 'self-isolate together', as Janet put it.

The boundaries of the household, then, were clarified and reinforced during lockdown. But their clarification also highlighted something unexpected: the fact that the household not only relied on a wide range of other social actors and community institutions in its everyday operations, but that the experience of family – especially as a network of care – was lived and mediated through relationships with those actors and institutions. All our interviewees described being cut off from these relationships as a major impact of the lockdown. As Natalie noted: 'We had nursery, we had a playgroup . . . and we had a childminder, and we had school, and we had my parents helping out'. At the same time, no fewer than three of our ten respondents were undergoing divorces that were put on hold by the lockdown. The boundaries of the household, in other words, proved not to overlap with the lived experience of family in the way public health interventions assumed. Under lockdown, the 'nuclear' family became suddenly 'unclear' (Simpson 1994).

### **Intimate Distinctions**

'I now have to be mother, teacher, and civil servant at the same time!' Helena exclaimed, sounding exhausted. The wife of a key worker, Helena suddenly found herself looking after her two-year-old and a seven-year-old alone, while working as senior manager. To top it off, most of the house was in boxes, in anticipation of a move now indefinitely postponed. But as befits an experienced manager, Helena had a plan. The boxes made space trickier to manage, but she could still manage routines – and time. After establishing a schedule for the children, she organised her working hours into the gaps that remained, writing emails early in the morning and late at night when the children slept, or after lunch while the toddler napped and the older boy read. Still, the concentration of her responsibilities in a single location and all 'at the same time', without the usual support of the children's father, grandparents and teachers, stretched her ability to cope. 'It's just not sustainable', Helena said.

In other cases, the loss of work or schooling suspended usual schedules and routines. Sarah was a single mother of two boys, who were nine and seven years old. She was a university student, and her final exams had been cancelled. As she said:

*Half of me is like 'yeah! I don't need to do anything. I got like six months off'. The other part of me is 'Oh my God, I'm gonna be so bored'. . . . The first couple of days, right, the kids played on the computer, I watched TV, we tidied up, cooked a bit and cleaned a bit, and now it's like, ok it's been a week and I need to do something.*

As the boundaries of the household solidified, boundaries within the household around space, time, roles and responsibilities were unsettled or broke down – and mothers working at home discovered a need for new distinctions to sustain a sense of self. While Helena's multiple roles as mother, teacher and civil servant were dispersed over different places and times, they were manageable; but

conflated in the same space and time, they quickly became unsustainable. Conversely, as Sarah's studies were put on pause, she needed to carve out new ways of being in the confined space-time of home. For these mothers, the creation of spatial and temporal boundaries between work, study, childcare and leisure time became crucial, if difficult, to maintain, especially when toddlers walked into home offices during online meetings or colleagues sent messages during story time.

While Helena created distinctions around the children's schedules, Nina took a different tack. Nina worked from a home office in her two-bedroom flat and described being 'terrified' of having to manage full-time work alongside childcare. But as the lockdown progressed, Nina and her husband made a point of splitting the day and the flat in half, creating space and time to be apart, which helped them to reconnect. 'So far, we are sharing half time every day, with childcare', she explained. 'Even if we don't go to work, we still have a half day for ourselves. . . . Just not to see each other's face. So, we almost miss each other at the end of the day'.

In his work on the relationship between self and identity in Pakistan, Martin Sökefeld (1999) notes that people may perform different – even contradictory – identities depending on social context, and that their ideas of self rely on movement between these identities in everyday life. Our study indicates that, when usually distinct social contexts and identities were collapsed together, tensions emerge, unsettling the self. But these tensions trigger the two attributes that Sökefeld identified as key traits of the self: reflexivity and agency. In responding to their new lockdown situations, the mothers in our study focussed on the often-difficult task of creating boundaries – in space and time between themselves and others – to separate conflicting roles. Their efforts were experimental, requiring continuous reflexive evaluation and readjustment. But this process, we suggest, was a crucial

means for locked-down mothers to sustain selfhood. Sarah, the university student, ultimately found that the opportunity to create new routines could be a source of joy and special connection with her children:

*And the silver lining is that we always complain that we don't have the time for this, that and the next thing. [Now] I get to see my kids every day, I can teach them what I feel they need to know, get to know them a bit better again, because this year I was really feeling like I wasn't seeing my kids at all. . . . They'd come home, I'd feed them, they'd go and do their homework, and that was it.*

For Helena, Nina and Sarah, the new distinctions in time and space they established created room for intimacy with their children and partners. Helena set aside space and time to be with her children in order to facilitate distance from them later, while Nina created distance in space and time to facilitate a sense of closeness with her husband. In both cases, intimacy proved to be not simply a question of proximity, but one of distinction and separation.

## **Conclusion**

At the outset of the United Kingdom's lockdown, the mothers we spoke to found themselves navigating an unexpected side-effect of 'social distancing' responses to the COVID-19 pandemic: the constant presence of their households. As their occupants and public health efforts alike worked to reinforce household boundaries, those boundaries became more rigid, and their misfit with the lived experience of family – as a network of care reliant on and mediated through a wide range of figures beyond the household – became more obvious. The intensities of household intimacies also became more acute. The conflation of disparate roles and relationships – mother, teacher, employee, partner – unsettled mothers' understandings of self, motivating them to experiment with new distinctions in space

and time, separations which in turn enabled their intimate relationships to thrive. Distancing, for these lockdown mothers, was indeed a social act that was crucial to sustaining selves and relationships in pandemic times.

*Hannah McNeilly is Lecturer for Medical Anthropology at the School of Medicine: Biomedical Sciences at the University of Edinburgh. She is a medical doctor and social anthropologist and has conducted research on neglected tropical diseases in Brazil, as well as on healing and care in the Afro-Brazilian religion Candomblé.*

*Koreen M. Reece is Assistant Professor in Social Anthropology at the University of Bayreuth. She conducts research on families and the ways they manage – and create – change in times of crisis. Her forthcoming monograph, *Pandemic Kinship*, describes how families in Botswana live with the AIDS pandemic, and the raft of governmental and non-governmental interventions launched in response.*

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▪ *Photo credit: Hannah McNeilly*

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# The pandemic through the eyes of Syrian agricultural workers in Lebanon, by Ann-Christin Zuntz and Mackenzie Kľema

For many marginalized people around the world, including refugees, the COVID-19 pandemic is not simply a health crisis, but it has also made existing poverty worse. Before the pandemic, more than 83% of Syrians inside Syria lived below the poverty line, while more than 90% of Syrian refugees residing in host communities in Turkey, Lebanon and in Jordan faced difficult conditions. Over the last year, many Syrian refugees lost their jobs as a result of the pandemic, with devastating impacts on their livelihoods. For the **Refugee Labour under Lockdown** project, researchers from the One Health FIELD Network, Syrian and Jordanian academics affiliated with the Council for At-Risk Academics and Syrian Academic Expertise, and Turkish practitioners from the not for-profit Development Workshop Cooperative, conducted interviews and

remote ethnographic research in Turkey, Lebanon, Jordan and Northwest Syria. We spoke with 80 Syrian agricultural workers, 20 agricultural intermediaries and 20 agricultural employers. In our study, 75% of Syrian workers temporarily lost their jobs, when restrictions on travel and public transport cut their access to fields and orchards, and 94% have seen their income decrease in the first year of the pandemic.

Given Syrian refugees' pre-pandemic levels of poverty, these findings are alarming. But what do they mean to a real-life refugee? Let's hear from Farhan, a Syrian living in Qob Elias, a provincial town in eastern Lebanon. Farhan is a refugee, but he also works as a "*shaweesh*", i.e. an agricultural intermediary, who brings together refugee workers and owners of fields, greenhouses and orchards. A *shaweesh* is a unique source of information about how refugee labour in agriculture is organised, and how refugees' working conditions and wages have changed during the pandemic.

Farhan's role is to coordinate seasonal workforces for 15 different agricultural employers in his region, and to organise jobs and transport for the workers in his group. Farhan also runs an informal camp for more than 400 Syrian refugees; most of the camp's inhabitants also work for him. Farhan pays their wages, but also collects a yearly fee of 600,000 LBP (approx. \$398) from each working family in the camp, which he uses to pay rental fees to the Lebanese man who owns the ground under their feet, as well as the camp's electricity bills. If Farhan and his workers have a disagreement, he can evict them; during the pandemic, this increases the risk of homelessness for vulnerable refugees with nowhere else to go.

To understand the intimate relationship that Syrian refugees have with their agricultural intermediary, we need to go back in time. Like many Syrians in pre-war Syria, Farhan had worked intermittently as a labour migrant in neighbouring Lebanon, where he had learned the business of the *shaweesh* from a

friend. By 2010, Farhan had assembled his own group of agricultural workers who regularly travelled with him from Syria to Lebanon:

*“[In March 2010,] I had a group of 50 workers, males and females [...]. The following year war broke out in my country, so I stayed in Lebanon with the workers I supervise, and I was joined by so many others. I had by that time between 100 and 120 agricultural labourers. Many sought refuge in Lebanon because of the war [in Syria]. [...] When the war broke out, we secured heating for refugees in the camp and managed our affairs. We lived there in summer and winter with the hope that the situation will stabilise in Syria in 2012 and we return home. But as you saw, the war evolved. As a result, the camp still exists until today. I first used to go look for and gather workers, but then when people began to flee Syria seeking refuge, they began to flock to our camp. I myself became a refugee, I could no longer go to Aleppo. As a shaweesh in the camp, I was tasked by the Lebanese authorities with monitoring who enters and leaves the camp and with addressing any dispute. We began to build a tent for every family seeking refuge in our camp and help them with available means. The UN also offered some help and refugees of the camp helped each other. Some would offer money, others a pillow, sheets etc.”*

As Farhan’s testimony shows, the COVID-19 pandemic is not the first crisis that he and his workers have lived through together – their shared story starts much earlier, in the early days of the Syrian conflict. His story also illustrates that in exile, not all Syrian refugees are alike: some, like Farhan, take on superior roles in work hierarchies and refugee communities because they serve as mediators between displaced people, locals and humanitarian agencies. As Farhan puts it, “a camp is like an institution with a manager and lower rank officials.”

In 2021, Farhan works with 110 female and 35 male Syrian workers, all from the same camp. In Lebanon, 85% of the Syrian workers in our study rely on intermediaries for finding jobs. As refugees, they often lack contacts and direct lines of communication with local work owners, knowledge of job opportunities and the bargaining power to hold employers accountable to verbal agreements. Each of Farhan's workers is paid 10,000 LBP (approx. 7 USD) a day, of which Farhan subtracts 2,000 LBP – to cover his own salary, but also to buy fuel for the buses that take Syrians to the field. While Farhan's own children go to school in Lebanon, more than 50 of his workers are under the age of 18, and the youngest are only nine years old.

When we spoke with Farhan in winter 2020, the agricultural season had just come to an end. During the autumn, his team of Syrian workers had been busy with harvesting potatoes and onions, now stored away in warehouses. The COVID-19 pandemic mostly affected their everyday lives through new regulations on the movements of Syrian agricultural workers:

*“A vehicle used to transport more than 30 or 35 workers. Now, the municipality only allows us to transport four or five female workers in one vehicle, and they have to wear masks and gloves. [...] Also, the municipality made us reduce the work shifts. We used to work three shifts, but now they reduced them to one and a half shift.”*

At the beginning of the pandemic, these movement restrictions caused job losses, increasing job insecurity for Syrian refugees on an already volatile agricultural labour market – it also meant losses for Farhan. In winter 2020/21, he earned 600-700 USD per month, compared to 2,500-3,000 USD before the pandemic.

Like many migrant agricultural workers around the world, Syrian workers have also been left vulnerable to COVID-19 due

to a lack of protections at work. Almost 40% of Syrian workers across study countries report that intermediaries and employers have not implemented any public health regulations during transport and at the workplace. While 97% of respondents wear a face mask during working hours, 84% are responsible for buying protective equipment themselves – most Syrians use traditional shawls to cover their faces. As workers in the informal economy, Syrian refugees do not have paid sick leave. Hence, many come to work even when they fall ill. According to Farhan, Syrian refugees in his camp are tested for COVID-19 by the UN every forty days, and so far no one has been positive. “We, the Syrians are anti-coronavirus and anti-all diseases”, Farhan says laughingly. As a precaution, however, he has banned big gatherings for weddings in the camp.

In Lebanon, the economic effects of the COVID-19 pandemic have exacerbated the country’s existing economic crisis – in refugees’ lives, this is felt most acutely through a loss of purchasing power. Agricultural workers’ wages were slightly raised in early 2021, but their actual worth in USD has declined because of the rampant currency inflation:

*“1,500 LBP were worth one dollar. Now, 8,550 LBP are worth one dollar. We used to buy a bag of sugar weighing 25 Kilograms for 18,000LBP, now we buy it for 90,000 LBP.”*

*“A female worker used to make a net wage worth four dollars per day, this dropped to 1.5 dollars now.”*

How do workers survive? In addition to being a recruiter and a landlord, Farhan also offers loans and advance payments to his workers:

*“They do some work and we take good care of them. We give them (money) as much as they demand, as much as we can, we help each other until God helps us improve our conditions.”*

Farhan's story shows how displacement, labour and public health crises intersect to create unique vulnerabilities for Syrian agricultural workers. One feature of Syrian refugee labour in agriculture is its informality, the interpersonal nature of work arrangements, and the lack of official complaint mechanisms. Social relationships at the workplace are an important mediating factor for shielding refugee workers from, or exposing them to, labour exploitation and ill-health. During the pandemic, closer and more trustful ties with an intermediary might grant workers' access to paid sick leave, and shape their decision to stay home, or keep going to work, when they experience symptoms of COVID-19. Conversely, there is a considerable risk that during the pandemic, financial dependency on intermediaries may have further entrapped Syrian agricultural workers in a cycle of debt, increasing the pressure on them to accept unsafe working conditions and low wages. We tend to think of the COVID-19 pandemic as a set of spectacular disruptions to established modes of working and global economies. However, findings from the **Refugee Labour under Lockdown** project indicate that for many displaced Syrians in the Middle East, the pandemic has entrenched problematic working conditions and relationships of dependency – and that is a problem.

*Dr Ann-Christin Zuntz is a lecturer in Social Anthropology at the University of Edinburgh and the Principal Investigator of the Refugee Labour under Lockdown project.*

*Mackenzie Klema is a recent MSc Environment and Development graduate from the University of Edinburgh, and Research Assistant for the Refugee Labour under Lockdown project.*

We will share findings from the Refugee Labour under Lockdown project during an online outreach workshop on 7th May 2021, 1pm UK time – more details soon on Twitter via @OneHealthFIELD



Ann will also discuss displacement and labour for Syrian refugees, seen through the eyes of the *shaweesh*, at a Refugee History event on 3<sup>rd</sup> June 2021.

All drawings are by the project's artist-in-residence, Sophia Neilson. Discover Sophia's amazing work on Twitter and Instagram @soofillustrates

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## **Maintaining entrepreneurial wellbeing in a pandemic, by Ben Spigel**

*This blog post was originally published on the website of ERICC Project (Entrepreneurial Resiliency, Innovation, and Change during the COVID-19 Crisis). Ben Spigel is an Associate Professor in Entrepreneurship and Chancellor's Fellow at the University of Edinburgh Business School.*

Today the ERICC project is pleased to release our first

report: *Maintaining Wellbeing in a Pandemic – A Guide for Scale-Up Entrepreneurs*. Drawing on over 130 interviews with high-growth entrepreneurs across the UK, we look at how the disruption and uncertainty of the pandemic are affecting the mental wellbeing of entrepreneurs and their employees.

You can download a copy of the report [here](#), but below we'll talk a bit more in-depth about the wellbeing crisis facing British entrepreneurs as well as several techniques entrepreneurs can use to support their own wellbeing and the wellbeing of their employees.

First, what is wellbeing and why does it matter? Wellbeing is a person's mental and physical wellness, representing their ability to successfully engage with their work and personal activities. Workers with poor wellbeing are less productive and more likely to leave the company. For entrepreneurs, wellbeing is critical to their ability to lead a company and react to the challenges of growing their firm during the pandemic. Poor wellbeing will reduce creativity and resilience and can ultimately lead to burnout.

This makes poor wellbeing a major issue facing the British entrepreneurial ecosystem. While there has been substantial government support for the financial health of businesses across the country, much less attention has been paid to the mental health of high-growth entrepreneurs. There is a major risk of losing an entire generation of high-growth entrepreneurs to permanent burnout.

It's almost too obvious to say that the pandemic is having a major negative impact on the wellbeing of high-growth entrepreneurs and their workers. There have been numerous news stories and studies of the emotional impacts of working from home under a cloud of health and economic uncertainty.

From our interviews, we saw that one of the biggest ways that entrepreneurs' wellbeing was impacted by the Covid-19 pandemic



was their emotional attachment to their employees. As one entrepreneur told us:

*We have a workforce of about 25 people. Just for me, it's like knowing that 25 people depend on me to provide the money for their children. And it's an amazing thing, but also a lot of responsibility.*

Founders had to take on new roles over the past 9 months, including confidant, therapist, and priest. Both by choice and by necessity, they are providing more emotional support to their employees to support them during this time. Those that had to furlough or make employees redundant over the pandemic said that this was almost emotionally traumatic and had a deep impact on them.

From our interviews, we identified several key coping strategies entrepreneurs can use to maintain their wellbeing and their employees' without overwhelming themselves. This infographic shows a few of these techniques and the experiences of entrepreneurs who used them.

One of the most important things we can do to support the wellbeing of entrepreneurs during this crisis is simply to talk about the problem. Unlike economic support for entrepreneurs, governments have fewer obvious options to support entrepreneurial wellbeing. But highlighting and discussing the issue and encouraging entrepreneurs to talk with each other about the challenges they're facing, is an important first step to ensuring that entrepreneurs aren't burnt out by this long and ever-evolving crisis.

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# **An oral history of the pandemic and the Lothian Diary Project, in conversation with Lauren Hall-Lew**

Lauren Hall-Lew is a Reader in Linguistics and English Language, in the School of Philosophy, Psychology, and Language Sciences at the University of Edinburgh. We talked to her about the Lothian Diary Project.

**Please tell us about the Lothian Diary Project. What are its goals? Also, what is the importance of gathering people's accounts of their lockdown experiences.**

We have eight staff members on the project, each of us with our own research goals, but the goal of the project overall is to gather accounts of lockdown experience in people's own words, rather than via a pre-populated survey. We do ask our participants to also complete a survey, in order to give context to their self-recording, but the focus of the analysis is really on the audio or video diaries that they create prior to taking that survey. These self-directed responses are important because they show us what people want to talk about (and what they don't want to talk about), and the way in which they talk about those things gives us a range of perspectives that might not be otherwise obtainable, such as from a survey. For example, participants often recount the single most difficult aspect of their lockdown experience, and many of these are presented with detail and description that only comes from someone speaking extemporaneously.

**The idea of using oral history as a research method is**

**intriguing. I was wondering how you are conducting the research during the lockdown?**

At the moment we are focused on our Knowledge Exchange outputs, rather than academic research outputs. These include an Oral History Archive for Museums and Galleries, Edinburgh, and a report for the Covid-19 Committee at Scottish Parliament. We're still collecting video diaries and will continue to do so until the end of May. However, the committee report is itself a piece of research, and at the moment we are working on that by generating automatic transcripts of the diaries which are then manually corrected for accuracy. The focus at this stage is therefore on the content of what's said, rather than a study of the video image or the speech.

**How did you recruit the participants from the Lothian citizens? How many volunteers have participated in the project so far?**

We have had approximately 125 contributors so far. We began recruitment in late May 2020, and have completed two stages now, and we're moving into a third at the moment. Stage 1 followed convenience sampling. Participants were recruited via social media platforms, adverts in local newspapers and radio, press releases, and word-of-mouth. Stage 2 of data collection was introduced to recruit underrepresented participants. The sampling strategy at this stage was to contact and partner with charities representing homeless, disabled, or other vulnerable individuals, as well as caregivers of any group. We established charity partnerships by running a targeted social media advertising campaign and an online interactive workshop for the Economic and Social Research Council's 'Festival of Social Science'. We also rented a local community space for three days to allow digitally excluded members of the public (e.g., those without reliable wifi access) to participate in person. We've just gotten funding to launch a third phase, with will specific recruit young people and their caregivers.

## **Can you tell us about some of your findings so far?**

As of now, most of the participants are from Edinburgh rather than the Lothians. Twice as many are female as are male. Most have an undergraduate degree or technical qualification, and most are between the ages of 16-64. Relative to the Edinburgh population, the sample has a greater representation of participants who are of colour (20%) and born outside the UK (27%). 20% are disabled and nearly 30% are LGBTQA+. One of the most important dimensions of variation is the day when the diary was recorded. The recordings span from May 2020 to February 2021, and so of course understandings of Covid-19 and “lockdown” changed quite a lot in the interim. For example, those recordings from early June 2020 are impressionistically rather different from those in July 2020, with the latter being more retrospective but also a bit more positive and optimistic. However, regardless of the day of recording or the state of lockdown on that day, one of the remarkable things we are seeing is a real resilience of the human spirit. Some of the most positive descriptions of the lockdown’s ‘silver linings’ come from participants living in some of the toughest of circumstances.

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## **Using network visualization to understand the spread of Covid-19, by Tod Van Gunten**

Like many infectious diseases, COVID-19 spreads most often through direct social contact. We are most likely to catch the virus through sustained social interaction: because of this, following a ‘15 minute rule,’ contact tracers seek to

identify individuals who infected persons have interacted with for a period of 15 minutes or more at a distance of under two metres. These interactions are most likely to happen with friends, family, co-workers and others with whom we share regular social relationships. In other words, the virus that causes Covid-19 tends to spread through our social networks.

Because of this, epidemiologists have long studied the properties of social networks and how they affect disease spread. Sexually transmitted diseases such as HIV/AIDS are an important example: because STDs spread through sexual contact, patterns of sexual interactions and the underlying social relations shape how a disease spreads in a population. Although SARS-CoV-2 (the virus that causes COVID-19) can spread through less intimate relationships, the same principle applies.

An important property of social networks is the variability between individuals in the number of such relationships (network analysts call this the *degree distribution*). This property may help explain how viral diseases spread. Individuals who interact with many people could spread a virus to more others than those who interact with fewer. Epidemiologists emphasize that the now infamous 'r' number, the number of infections resulting from a single prior infection, is also varies widely. Most COVID-19 infections result from a small number of previously infected individuals: in a study of the pandemic in Hong Kong, 80% of cases resulted from around 20% of previously infected individuals. This helps explain the importance of so-called super-spreading events: either because they have an usually large number of social contacts, or just happen to enter a crowded space while infected, some individuals will spread the virus to a large number of others. Others will not spread the virus at all.

Thus, social interaction patterns affect the transmission of Covid-19. But happens *after* a such a super-spreading event occurs? Just as individuals will infect a widely varied

number of other people, events could give rise to a widely varied number of other events. Understanding this could help explain how a virus like SARS-CoV-2 moves through a population – and thus perhaps help control it. A superspreading event occurring in, say, a church may have different implications for viral spread than an event at a bar. If (for example) most churchgoers tend to interact with others in the same church-going community, whereas bar patrons have much wider social networks, then the bar event could give rise to many more infections and subsequent super-spreading events, than the church event. Just as there is a network between individuals, there is a network of events. This aspect of disease spread is much less studied.

As a sociologist studying social networks, I was thinking about these issues when I stumbled across a trove of data on the web page of the Singapore Ministry of Health. In the early months of the pandemic, health authorities in Singapore posted the results of their contact tracing programme online in daily press releases. This anonymous information included contacts between pairs of infected individuals and associations between individuals and infection clusters identified by the authorities. I realized that this information could be used to visualize the network of COVID-19 infections, and perhaps teach us something about these broader patterns of spread.

Singapore turned out to be an interesting location to explore these questions because of social interaction patterns in the population and peculiarities of the local pandemic. After seeing its first COVID-19 cases in early January, public health authorities rapidly implemented a suite of comprehensive public health measures that were initially fairly successful in controlling the virus. However, beginning in mid-March the city was hit by a large outbreak occurring primarily among the city's migrant worker population. The Singaporean economy is highly reliant on

guestworkers (many from India and Bangladesh) who live in cramped dormitories. This was an ideal ecosystem (from a virus perspective) for rapid spread of SARS-CoV-2. Roughly speaking, these dormitory clusters are like the super-spreading events discussed above.

While the spread of the virus *within* dormitories was easy enough to understand, I wondered how it spread *between* them. In other words, if each dormitory was a kind of super-spreading event, what did the network between them look like? The fact that workers lived in close quarters within dormitories didn't explain how the virus spread so quickly to many different dormitories. It was also unclear how the virus got into the migrant worker population in the first place. To try to answer these questions, I used the contact tracing data from the Ministry of Health web page to visualize the network of COVID-19 infection. The result is the image above.

Network visualization gives researchers insights into patterns in data that can't otherwise be easily seen. A network diagram represents relationships between different kinds of entities – which could be individual people, or anything else – as points connected by lines. In this case I had two kinds of entities: people infected with SARS-CoV-2, and locations such as dormitories where many infections occurred. I represent individuals as squares, and clusters as circles. The lines in the picture show whether two individuals had a known social connection, or whether individuals were associated with a particular cluster.

Network diagrams like this often suffer from the 'hairball' problem – there are too many points and lines to make sense of the data. To simplify, I represented those individuals who were *only* connected to one cluster (and to no other individuals) by using the size of the circles to reflect the size of the cluster. I then used colour to show whether individuals held a permit for migrant workers, or (in the case of clusters) what percentage of the individuals in each

cluster were guest workers.

We can think of this figure as capturing something like the network between super-spreading events or infection clusters as introduced above. There are a few important lessons we can take away from this. First, a large proportion of cases occurring during the time period studies are connected to in this network. This supports the starting assumption of my work – that COVID-19 tends to spread through social contacts – and also suggests that the Singaporean health authorities were very effective in uncovering these networks.

More importantly, one cluster at the centre of the network (labelled cluster 1) is connected to many more other clusters than any other cluster. Cluster 1 is connected to around eight infection chains (a chain is a series of infected individuals resulting in at least one additional cluster or event). No other cluster seems connected to more than two infection chains. Based on the timing of infections, cluster 1 seems to be the first cluster in the network. In other words, cluster 1 was a kind of ‘super-super spreading event’ that not only produced many infections, but also produced many other chains of infections resulting in other clusters. Cluster 1, which corresponds to a construction site, is also *not* composed of a majority of guest workers. However, several infection chains coming from this cluster resulted in later infection clusters in dormitories, where a sizable majority of infected individuals were guest workers.

A reasonable inference from this diagram is that the construction site was the critical pathway through which the virus spread into the guest worker population in Singapore, spreading from this work location to many residential locations (dormitories). In so doing, the virus also ‘jumped’ from one segment of the Singaporean population to another. Once present in the guest worker population resident in dormitories, the virus spread between dormitories and other locations, producing further infection clusters. Although



non-guest workers were exposed to the virus (and sometimes seem to have spread it between clusters), this infection pattern produced few clusters in the non-guest worker population. While many infections resulted from these later clusters, they did not each branch out into multiple chains of infections, further clusters, and so on.

This research was exploratory, and so conclusions must remain tentative. Moreover, Singapore is unique in important ways, and we should not forget that this network occurred in the context of relatively effective public health measures. Nevertheless, an important lesson is that patterns of social interaction occurring at broader scales – such as whether individuals interacting in one setting, such as a construction site, also interact with individuals in other settings, such as a dormitory – govern the spread of the virus. Had public health authorities been aware of these interaction patterns, they might have been able to prevent a large outbreak. Hopefully, epidemiologists and other researchers will incorporate these larger-scale networks into their understanding of disease spread.

*Tod Van Gunten is Lecturer in Economic Sociology at the University of Edinburgh since 2017. His recent publication “Visualizing the network structure of Covid-19 in Singapore” appeared in the journal Socius: Sociological Research for a Dynamic World.*

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**Collecting Covid-19: an initiative to document the**

# University's community response to the pandemic, by Lorraine McLoughlin and Sara Day Thomson

The Centre for Research Collections (CRC) at the University of Edinburgh – which includes collections housed in libraries, archives, galleries, and museums – launched the *Collecting Covid-19 Initiative* in late April 2020. The *Initiative* invites staff, students, and anyone affiliated with the University to donate any materials that document their experiences of the pandemic and lockdown. Web and social media content, photographs, videos, art, and all other materials are welcome. The *Initiative* is led by the Archive team, who will consult with a collaborative advisory group from different areas of the University as the collection develops. In preserving a range of materials and formats for the long term, we aim to prevent gaps in memory and experience.

In this post, we share the ways the Archive team at the CRC makes decisions about what to collect. We discuss how the *Initiative* aligns with existing collecting policies but also provides us with an opportunity to challenge conventional methods. 'Active collecting' – implemented to document the pandemic as it unfolds – has led us to explore approaches to capturing records contemporaneously in response to a major event. Though these approaches have been introduced at a pace, they are not temporary measures. Rather, they are lasting innovations that will support a more responsive (and therefore representative) collecting of the University's diverse communities and activities.

**About the CRC and Archival Collecting**

The CRC preserves and provides access to the University of Edinburgh's many and varied historic collections, from anatomical specimens and artworks to University statutes and conventions. Archival holdings reflect a broad spectrum of events and life experiences. The CRC also documents University governance and research accomplishments and preserves some less-easily categorised examples of University life, culture, and events.

The University community – a broad term to describe individuals and groups affiliated with the University of Edinburgh – usually engages with the Archive by donating letters, notebooks, sketches, diaries, theories, poems, artworks, ruminations, and all sorts of unique memories. Since the advent of digital technologies, these unique materials are often donated to the Archive in digital formats.

The CRC, in response to this shift, has undertaken the development of a digital preservation programme to look after born-digital and digitised materials. However, the selection of material, digital or analogue, for long-term preservation is a highly nuanced process. Archival content (whether digital, physical, or both) should be unique, authentic, and highly valuable. Assigning value – the ultimate responsibility of archival appraisal – is a subjective process which is very difficult to define. But attempt to define it we have done none the less.

Over the past three years, we have been developing a robust methodology for documenting *how* and *why* materials are selected for preservation in order to provide accountability for collecting decisions. The methodology allows archivists responsible for selecting materials to describe decision-making and enable us to identify gaps in historical memory. The process is both iterative and highly dependent on external variables. Therefore, what we collect (and how we do it) should and does change over time. Our methodology is based on the fundamental principle of providing evidence and

transparency.

## **Active Collecting in Response to a Crisis**

Since April 2020, the Archive team has been ‘actively collecting’ materials – using methods to source and select content as it emerges – for the *Collecting Covid-19 Initiative*[i]. The open call has been left deliberately broad to encourage participation from individuals and groups doing core ‘COVID-related’ work *as well as* those whose lives have been changed in other, less apparent ways.

The traditional archival method of collecting materials at the end of a project, or even at the end of a researcher’s career, involving multiple conversations and usually in-person donation, does not support active, contemporaneous collecting. Therefore, the Archive team, working with the Digital Library Development team, launched a web form for members of the community to submit donations remotely.

The Digital Submission Form for the *Collecting Covid-19 Initiative*[ii] supports some basic archival procedures to ensure confidence in the security and confidentiality of submissions while making it simple to make a donation. Members of the University community can donate their materials by filling in a few pieces of information about themselves and their materials, attaching the relevant files or including a URL, and hitting ‘Deposit’. We use the information from the Form, ethically and in compliance with personal data legislation, to help us organise and present archival materials in a way that reflects their original intent. It also provides valuable context needed by users to support interpretation and analysis of materials in the future.

The Digital Submission Form allows us to capture responses *now*, while the pandemic and lockdown are on-going. In times of crisis when normal life is severely disrupted, resources and attention are diverted to cope with the crisis, which of

course, is how it should be. However, this diversion also leads to gaps in shared memory that could help support decision-making in future crises as well as providing context and insight into personal experiences. Therefore, the *Initiative* will remain open for as long as the pandemic is with us and public health-related restrictions are in place and, likely, for a long time after.

### **Covid-19 and New Archival Methods for a New Future**

As mentioned, many of the materials submitted to the *Initiative* are born digital, and many of those are web-based. These web-based submissions, from blogs to Twitter feeds, have particular value as they represent the most prolific way people have been communicating during a pandemic that has prevented families, friends, and professional teams from interacting in person.

Inviting the donation of web-based content is an important strategy for active collecting. While the Archive collects and preserves digital formats, until the outbreak of coronavirus, there was not a systematic method in place for collecting web-based content. As previously mentioned, historically, the archivist intervenes at the 'end of life' of a collection. However, archivists don't have time to wait for born digital materials, like websites, to amass over time and we don't have a crystal ball to predict what content will grow into cohesive collections.

Web archiving, using bespoke tools, provides a method for capturing contemporary, born digital resources in a rapid, proactive way. Capturing content from the live web as soon as possible is vitally important because web resources disappear or change more quickly than other types of digital media. In a paper from 2015, the UK Web Archive reported that in just two years, 40% of websites collected in the national web archive had disappeared from the live web[iii].

The availability of new, robust tools has made it possible for the Archive team to capture some selected web-based materials manually. In fact, this entire blog – including all posts and linked citations – is being archived as part of the *Initiative*. This archival capture of *Covid-19 Perspectives*[iv] provides an authentic record of how CAHSS researchers have responded to the pandemic and lockdown. It will allow future researchers, looking back on this historic event, to learn more about how CAHSS research contributed to our understanding of the virus and its effects on individuals and society.

To undertake web archiving at scale for University-wide web resources about the pandemic, the Archive team are partnering with the UK Web Archive[v] at the National Library of Scotland. Working with the Web Archivist at NLS, the Archive team will build a collection of web resources created by the University and its communities using the UK Web Archive's infrastructure and guidelines.

## **Conclusion**

Active collecting, and in particular web archiving, provides a meaningful glimpse into the future of archival practice at the University of Edinburgh and for the sector more generally. In particular, it provides a blueprint for the development of practices that reflect contemporary ways of communicating and sharing information. Digital resources can exist in multiple forms and can be accessed simultaneously in different places on different platforms at the same time. They can evolve throughout their lifetime for different purposes and become transformed through sharing and re-use.

Digital technologies, because of their nature, enforce the plurality of authenticity and perspective in our shared memory. They enable the creation and publication of resources outside of typical structures, diversifying (and democratising) public and academic discourse. It has spurred archives to consider how to adapt our methods of communicating

so that they reach all the diverse communities creating culturally and historically important resources.

Covid-19 has imposed new ways of working and interacting – many of which have led to difficulty and frustration – but many of which have catalysed change already underway. The *Collecting Covid-19 Initiative* has brought rapid changes to archival working practices but has also provided an opportunity for us to forge new relationships with the communities we serve. In fact, the *Initiative* is situated within a much wider conversation currently on-going within the Archive team to interrogate and refine our working practices.

This investigation of *how* our collections develop provides us with a greater understanding of *who* is included in our institutional memory and how they are represented. We aim to give far greater priority to active collecting in order to broaden the nature of material we hold beyond those highlighted in traditional power structures.

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*Sara Day Thomson is the Digital Archivist at the University of Edinburgh's Centre for Research Collections. Her background is in research and development in digital preservation and web and social media archiving.*

*Header image: Opening event for the Video Wall and MakerSpace at the Main Library (November 2019) © The University of Edinburgh.*

[i] Collecting Covid-19 Initiative:

<https://www.ed.ac.uk/information-services/library-museum-gallery/crc/collecting-covid-19-initiative>

[ii] Collecting Covid-19 Initiative Digital Submission Form: <https://www.ed.ac.uk/information-services/library-museum-gallery/crc/collecting-covid-19-initiative>

[iii] A. Jackson, 'Ten years of the UK web archive: what have we saved?', UK Web Archive blog (18 September 2015), <https://anjackson.net/2015/04/27/what-have-we-saved-iipc-ga-2015/>

[iv] Archival capture of Covid-19 Perspectives: <https://conifer.rhizome.org/sdaythomson/cahss-covid-19-perspectives-2/list/homepage-and-linked-policy-statements/b30/20200826154722/https://blogs.ed.ac.uk/covid19perspectives/>

[v] UK Web Archive: <https://www.webarchive.org.uk/>

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## **Government by numbers?, by Tamar Pitch and Roger Jeffery**

The original French version of this piece: Tamar Pitch and Roger Jeffery: 'Le gouvernement en chiffres', in *Tour du monde de la Covid-19*, (eds) Shigehisa Kuriyama, Ota de Leonadis, Carlos Sonnenschein et Ibrahima Thioub, 2021, Paris: Editions Manucius

Two questions: Government of what? Which numbers?

Every day at 6pm Italians waited for the news on Covid-19



delivered on TV by one member of the 15 task forces instituted to deal with the emergency. In Britain, daily news conferences at 5 pm were hosted by a kaleidoscope of government ministers, usually flanked by a senior scientific adviser; in Scotland at 12 noon, the First Minister a constant presence. These press briefings dominated the news broadcasts from 6 pm onwards. In Italy, we all watched as we had little else to do, locked in as nowhere else in Europe (apart from medics, workers of "fundamental" business, etc.: quite a large number of people exposed to the contagion). All the media focused on numbers and targets.

Increasingly, governments around the world said that they were following the science. Science involves numbers. Sometimes, media, government and epidemiologists tried to make these numbers more meaningful (such as using rates per million population, rather than totals). Sometimes, other figures were added to the cocktail. By May, the Scottish government offered daily updates on tests (total, numbers positive and negative), deaths (by two different reporting systems, classified by age, sex, setting and location), numbers in hospital (intensive care or not), and numbers of staff off sick, as well as some others of how the pandemic was progressing. But the daily totals, unadorned and simplistic, still dominated the headlines.

What are these numbers supposed to say? Why these numbers and not others? As we soon discovered, apart from the numbers in intensive care (which at least conveyed the pressure on scarce medical resources), the headline numbers were confusing and misleading. Too few tests done, no idea how many people had been infected but were asymptomatic.  $R_0$  suddenly entered the public vocabulary: but only a tiny number of people knew what it meant, let alone how it was estimated. Yet these data were, according to politicians, directly responsible for their policy decisions.

Who did the interpretation? This is the age of modellers,

whether in climate change, infectious diseases, or election predictions. Medical experts, virologists, epidemiologists, and a plethora of other scientists took over our screens, media, social media included. They battled with each other, giving slightly or even largely different interpretations of the data. Slowly it was admitted that models were only as good as the data they used. Some pretended that what they said was the "truth", being based on "science". Others admitted that they dealt with uncertainties; but politicians demanded a fig-leaf to cover their own confusion. We needed epistemic humility; we got overconfidence. So, we entered a state of dystopia and became more afraid. The governance of the epidemic was apparently delegated to "experts" who changed their minds but never admitted they might have made mistakes. Questioning the power of institutional experts doing health metrics is difficult, requiring substantial counter-expertise: who can stand up to dominant discourses? So we accepted to be locked in, as perhaps the only possibility to save our national health systems, despite the muddle visible among those in power.

And where were ethics among the clamour of numbers? Ethical issues came to the fore when front-line staff made visible the tragic choices they were asked to take in a dearth of intensive therapy places. Who to admit to a respirator? Were age, other pathologies or disabilities relevant or desirable criteria? In some countries they were explicit; elsewhere, one could just guess if one would be resuscitated. So, numbers again, in this case of ventilators, but numbers that posed difficult ethical (and political) questions. Why so few ventilators, so few masks and so little personal protective equipment? In Italy, why so many deaths in Lombardy, until then extolled as having the best health system in Italy and maybe in Europe (though Ota De Leonardis and her team had been denouncing it for years)?

Then in both Italy and Scotland we discovered how many people

had been dying in care homes for the elderly. Only in mid-April did we learn that the trumpeted death totals were only of those who died in hospital; care-home deaths, deaths in hospices or at home, deaths where Covid-19 was suspected, or as a contributory factor but not tested for: all had been missing. Terrible deaths for the elderly, with no relative present, no funerals: lines of army lorries carrying corpses to the crematoria in the night. Is such "harvesting" a problem? After all, most of them were old people, some with dementia, others with numerous pathologies. Better they died than younger people, right?

As older people, we find it blackly humorous that, until just before the epidemics, we were told that we were to be considered young until at least 75 years of age. Because: as baby-boomers, most of us have pensions, we are precious consumers, we travel, we look after grandchildren and subsidize our children. But now we are proclaimed old at 60 or 65. And the idea circulated that our lockdown should last another year. We are more at risk if we get Covid-19, and (especially, we think) we might then make the health system collapse.

Mathematical, 'nudge' models, badly constructed, variously interpreted, were yet used as justification by our national and regional governments for their decisions. In Britain, a Minister said that the virus created age-discrimination, not the government. The original policy was to let us catch the virus, and for the elderly to die in unknown numbers, until the epidemic worked itself out. Yet these models, on closer scrutiny, lacked any validity. An incessant flow of ordinances, contradicting one another, and arbitrarily interpreted by the police, rained on us from different institutional agencies, but who took responsibility?

We were (and are) constantly reminded of our primary individual responsibility: staying at home. "It's up to each and every one of us" was repeated. So, after an initial show

of solidarity and communion (people singing from balconies, putting out the national flag), we turned into informers, spying on people walking outside, denouncing the solitary runner, sometimes even attacking them.

Having dismally failed at primary and collective prevention, our governments put all the responsibility of preventing the collapse of the health system (plus flattening the curve of contagions) onto individual citizens. Here are (at least) two major contradictions: on the one hand, while the onus is on each citizen, we are not really trusted to comply, therefore the flow of decrees and ordinances; on the other, many cannot comply. Not only those who have to work anyway, but also those without a house, or only a very small one, or who must live with violent partners.

No, we are definitely not all on the same boat. Some have no boat, many have a small boat, a few have a yacht. This epidemic, and the measures taken to confront it, starkly show and deepen social, economic, and cultural inequalities, along the lines of gender, class, and "race". All of which calls for collective responsibility, i.e. the State and its institutions. The "State" doesn't trust us; can we trust the State? Can we trust governments who have done nothing to prevent the pandemic (which they should and could have done), nor its effects on the more vulnerable? Can we trust governments which hide behind "experts" while failing, ethically and politically, to admit their responsibility to analyse "expert" advice on the best policies to pursue?

Italians just entered phase 2. We can go for a walk and visit our "congiunti". This word is much debated: who does it refer to? First spokesman for government said: relatives up to the 6th grade. Anxious consulting of anthropological expertise on kinship systems followed. Second spokesman said: stable relationships. Third spokesman clarified: definitely not friends!

*Tamar Pitch was a professor at the Law Department of the University of Perugia, where she taught philosophy and sociology of law. Her books, articles and research focus on crime and criminal justice, deviance and social control, gender and the law, human rights. She is the editor of the journal Studi sulla questione criminale, and is a member of the Italian National Bioethics Committee.*

*Roger Jeffery is a Professorial Fellow in Sociology, University of Edinburgh, and Associate Director of the Edinburgh India Institute. His research has focused on the politics of health, childbearing, education, pharmaceuticals and clinical trials in South Asia. He is currently a Co-Investigator in the South Asian Nitrogen Hub, and writes about the impact of India on Edinburgh.*

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## **Vaccination time, by Janet Carsten**

21<sup>st</sup> February. Yesterday we went to get vaccinated. Despite the grey, damp Edinburgh morning, it seemed like a day of celebration from which we (my husband, Jonathan, and I) emerged elated. A red letter day on a calendar with almost nothing marked on it. Everything at the mass-vaccination centre on the outskirts of the city seemed to run on oiled wheels. We arrived a little early for our simultaneous and precisely-timed 8.51 appointments; by 8.51 we were already on our way out. Staff were cheerful and kind. A volunteer vaccinator who told me she was a dentist, normally on a four-day week, checked routine questions before giving me my injection. Had I had any vaccinations in the last six months? 'No', I responded without hesitation. She enquired brightly

about a possible flu jab in the autumn. I had forgotten that, and we laughed.

So much gets forgotten in the strange, elastic time that we have been living for the last year. A time out of time, as many have said, much of it hard to differentiate in retrospect, marked by different small rhythms. The daily ones of domesticity that tend to merge into each other – work, reading and writing, mealtimes, evening films. When did we see that? When did I read that? Monthly rhythms – the changing seasons, the expansive luxury of long novels, Dickens suddenly and unexpectedly coming into his own. Markers of time. The walks that have been repeated daily and are seasonal too – occasions to note small changes in the neighbourhood or to lose oneself entirely in trains of thought. A time of multiple immersions when immersion itself seemed like a good way to lose time, lose oneself.

Vaccinations have also marked off different generations of family time through the 20<sup>th</sup> century. In the past few weeks, since they have been on the horizon, I've been thinking about my mother, Ruth, a polio victim in 1916 or 1917 at the age of five. But she didn't think of herself in those terms, and in any case referred to her affliction by the older (and already outdated) term, 'infantile paralysis'. Despite life-changing illness in early childhood, family tragedy in her twenties, losing her right to citizenship, and becoming a refugee in the 1930s, Ruth never saw herself as a victim, but as unbelievably lucky. She spoke occasionally of her vivid memory of the last day she had been able to run before being struck by the diphtheria that had been closely followed by polio. And she was a fierce advocate of immunisations. Born in the mid-1950s, I would have been among the first groups of children in Britain to receive a routine vaccination for polio in early childhood – with no parental doubts about the benefits. Not long after her death, those recollections of my mother's, and my own childhood memories, were brought to mind when, in the

mid-1990s, I took our baby daughter for her inoculations. The nurse at the GP clinic, whom I told then, became visibly and surprisingly moved. I recall those memories again now, in 2021, as we are among the first people in the world to receive vaccinations for Covid19 in an immaculately organised centre with wonderfully friendly and efficient staff. What unbelievable luck.

*Janet Carsten is a professor of social and cultural anthropology at the University of Edinburgh. She is also a Fellow of the British Academy, and author of many books including Blood Work: Life and Laboratories in Penang (2019).*

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## **Covid-19 and football finance, by Mason Robbins**

*The full impact of COVID-19 may not be realised for years to come, with the associated uncertainty forcing existing and potential broadcast and commercial partners to consider the amount they are willing and able to invest in sport. (2021 DFML, Deloitte, 210127)*

In March 2020, the last of the European football leagues decided to stop operations indefinitely after a series of players tested positive for COVID-19. The last top-flight match played in front of a full crowd was the UEFA Champions League tie between Atlético Madrid and Liverpool, played at Anfield, Liverpool, on the 11 March 2020. The football industry is still recovering, and questions need to be asked about its preparations, resilience, and lessons. On the 16 May 2020, the German Bundesliga announced that it would be the first of the big-five leagues to return to competition with

Spain (11 June), England (17 June), Italy (20 June), France (season abandoned), and Champions League (7 August) following soon afterwards. The stoppage period in play provides the opportunity to comment briefly on these conclusions about what can be called 'Before-Covid' (BC) and the early reactions to an 'After-Covid' (AC) response to the changing nature of elite football business operations.

COVID-19 has directly impacted the end of the 2019/2020 season and the beginning of 2020/21 season across several areas, namely around the broad variables that affect fans' return to stadiums. Fan and supporter interactions with football are impacting the commercial and broadcasting partnerships due to the challenges transiting to a digital environment. This reflects the evolving nature of the football finance rankings ecosystem where all actors are partners, and success depends on multi-directional relationships and collaborating towards a common goal. Building on this, Real Madrid's Director of Digital Strategy breaks the COVID-19 recovery plan into three stages: 1) engage with fans; 2) support partners; and, 3) remain socially responsible. COVID-19 has accelerated our digital strategy [Real Madrid Director of Digital Strategy, Web meeting, 20200514]. The current pandemic has seen the football industry struggle. The industry is moving away from brands, athletes, and individuals to a unified partnership; the industry has to learn how to integrate fan into the fan-less environments; innovation will drive sponsorship and branding in the future. 'Covid has resulted in five years of research and development physically, technologically, and methodologically condensed into three months, what we are doing today was only dreamed of by executives back in January (2020)' (Real Madrid Chief Officer, Web meeting, 20200514).

The knock-on effect, along with the changing nature of national governmental regulations means that clubs and football organisations will face another season of uncertainty, especially around matchday, commercial, and



sponsorship revenue sources. Deloitte's Sports Business Group has highlighted how, whilst some clubs are better positioned to handle the pandemic's impact, the industry has to experience a transformative process of re-evaluating business models and accelerating their digital strategies. The Deloitte highlighted:

*[c]lubs' now more than ever, must keep their eye on the ball' to pursue further growth. COVID-19 has emphasised that the clubs who can remain agile, transform and innovate and have a unique opportunity to stabilise and grow, whilst those that accept the status quo risk standing still or even falling behind the pack in these uncertain times. (Deloitte Manager, 20200630)*

The first few months in the AC era have seen clubs, federations and sports organisations working hard to mitigate the total shutdown's impact whilst attempting to remain connected to supporters, meet a contractual agreement with sponsors, and maintain revenue generation opportunities. According to Deloitte, the 2020/21 season will be directly impacted by COVID-19, across several areas:

- There will likely be a broad range of scenarios impacting the timing and nature of fans' return to stadiums.
- Broadcasters and commercial partners will face economic challenges due to the changes in both fans' attendance and consumers' interaction with the sport.
- Clubs should expect uncertainty in their matchday revenue forecasts until further Government guidance is offered regarding crowd capacity at sporting events.

Deloitte's data demonstrates that whilst the football business industry continues to grow; it is now even more critical to engage with digital technologies in connecting clubs, stakeholders, and supporters. It has become imperative for

sports organisations to understand the supporters' base whilst adapting the matchday experience. In turn, knowing a supporter base will help to drive commercial revenue opportunities and the ability to explore new business models and revenue streams.

Whilst some clubs will be better positioned to weather the storm than others, COVID-19 will undoubtedly have implications for all. Each club faces a struggle to retain and grow revenue from commercial and sponsorship agreements, whilst also navigating the future uncertainty of matchday revenues.

*The COVID-19 pandemic has provided an impetus for clubs to rethink and recalibrate their wider strategic objectives and business models to ensure a strong recovery from the current situation. In particular, the focus on both internal and external digital capabilities has necessarily accelerated as digital interaction quickly became the dominant way in which clubs could engage with their staff and fans. (2021 DFML, Deloitte, 210127)*

In conclusion, the current global climate has rapidly changed the football business industry in just a few months of 2020. The lessons mentioned above are provided to acknowledge and highlight what various football organisations are doing in light of COVID-19. Most importantly, this Covid comment draws out the lessons learned from the last thirty years of evolutions, interactions, and innovations found to play a role in the football business ranking ecosystem and its nexus of actors. It is still early in the global pandemic, and a lot will change in the coming months and years. What can be concluded is that elite clubs are beginning to evaluate their commercial and brand assets, which the football business rankings have highlighted, and utilise their global reach to provide support and improved resilience against this and future global pandemics. This remains a fertile area for future research.

*Mason Robbins is the Global Program Manager of the University of Edinburgh- FC Barcelona Partnership. He has recently completed his PhD in Science, Technology and Innovation Studies.*

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# **The impact of COVID-19 on individuals with and without eating disorders in the UK, by members of Eating Disorders and Behaviours Research Group**

*This blogpost is written by the members of Eating Disorders and Behaviours Research Group: SiennaMarisa Brown, Marie-Christine Opitz, and MacKenzie Robertson.*

The University of Edinburgh's Eating Disorders and Behaviours (EDB) research group [1] was established Autumn 2019 as an effort to consolidate postgraduate research (PGR) candidates with eating disorders and/or behaviours as a general area of interest. Principally led by the School of Health in Social Sciences' Dr Helen Sharpe, Dr Emily Newman, and Dr Fiona Duffy, the research group now consists of approximately 15 members and, during the COVID-19 coronavirus pandemic rapidly[2] created, conducted, and published two studies—one interview- and one survey-based—on the perceived impact of COVID-19 on individuals both with and without eating disorders in the UK.

The first study, “A qualitative exploration of the impact of COVID-19 on individuals with eating disorders in the UK” (2020), was the first in depth interview approach with adults with mixed eating disorder presentations in the UK during COVID-19. The second study, “Exploring changes in body image, eating and exercise during the COVID-19 lockdown: A UK survey” (2020), used survey responses to investigate the perceived impact of the COVID-19 related lockdown in the UK on people’s eating, exercise, and body image.

### **An interview-based exploration of the impact of COVID-19 on individuals with eating disorders in the UK [3]**

What did we find? Across all interviews, we found that three general themes were important: how participants were restricted in the way they could socialize, how they had to change their daily routines and how differently they could be supported by professionals regarding their eating disorder.

#### *Social Life*

Not being able to visit friends or family meant that participants felt lonelier and had more time to think about food. If they were living alone, they usually had less support from people they would otherwise see regularly. However, if they had a supportive partner or family, they sometimes had *more* support than they usually would have throughout the day. Finally, those who managed better during lockdown (despite having less support available), perceived this as an achievement for themselves.

#### *Daily Life*

Routine and structure were generally seen as helpful when dealing with disordered eating. New mealtime routines with supportive family members were perceived as beneficial. However, working from home, living alone and sudden changes in daily routines led to more disordered eating for participants who felt overwhelmed by these changes and who had less support

than they usually would have at work or during leisure time activities. Not being able to leave the house much also meant that participants intensified their exercise routines to get the most out of it. In addition, participants had problems keeping their eating disorders hidden (while food shopping or when they lived with family/partners), which was perceived as highly stressful. Others used their isolation to avoid uncomfortable questions about how they were doing; avoiding these questions meant that they did not have to be confronted with their disordered eating.

### *Professional Support*

Due to restrictions in face-to-face contact, the ways of accessing professional support had to be changed. Some participants struggled with this new format, while others appreciated the anonymity of online support. Most participants felt that they did not feel deserving of more support, especially with mental health services being overstrained.

### **Key points:**

Overall, the lockdown period was a stressful experience for all study participants. Based on our ten interviews we further found:

- The impact of the lockdown measures was highly dependent on **available resources** (such as participants' living situation, available personal support and amount of responsibilities held during this period)
- The impact of the lockdown measures was highly dependent on **how severe the eating disorder was at the beginning of lockdown**; more severe eating disorder symptoms were associated with more difficulties when dealing with disordered eating during lockdown
- Changes in routine, restrictions and regulations caused significant stress for people with eating disorders and will likely **continue to cause significant stress beyond**

**the lockdown period**, as routines have to continuously be adapted; worries about the future and how routines will have to change (even if the spread of the virus can be contained) need to be considered in the future

### **Exploring changes in body image, eating and exercise during the COVID-19 lockdown: A UK survey [4]**

The COVID-19 related lockdowns have had a major impact on our daily routines, including how we access food. In this study, we explored how lockdown measures might be impacting people's relationships with their body, food, eating, and exercise. We were particularly concerned with how people with pre-existing eating difficulties, such as people with eating disorders, were coping with these changes.

We asked 264 adults in the UK to tell us about their experiences in lockdown. Initial findings suggest some people report that their relationship with their body, food, eating, and exercise either improved or worsened. Importantly, some groups appear to be more vulnerable to negative effects including women, people under 30 years old, and those with a current or past eating disorder diagnosis. These groups reported an increased concern about their appearance and more difficulties regarding food, eating, and exercise.

This is an ongoing project and future analyses will be important for increasing our confidence in these findings; however, alongside similar results from other studies, the findings suggest that women in particular may be experiencing more mental health difficulties as a result of the lockdown, including increased disordered eating. Additionally, results suggest that we might see an increase in demand for eating disorder services across the UK as current clients may experience worsening symptoms. This highlights the ongoing need for more accessible eating disorder resources and the critical examination of public health campaigns aimed at weight loss that are likely to increase weight stigma and

perpetuate eating disorders.

[1] The University of Edinburgh's Eating Disorders and Behaviours research group can be contacted via email at [research.edb@ed.ac.uk](mailto:research.edb@ed.ac.uk).

[2] As COVID-19 is a rapidly evolving situation, the EDB group aimed to capture perceived effects in real time; thus, a 'rapid study'.

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## **Religion, trust and Covid-19 in Congo, in conversation with Emma Wild-Wood**

In this interview, Dr. Emma Wild-Wood from the School of Divinity answers our questions about her research project on the responses of the religious communities to the pandemic and their contributions in building trust as a component in good public health.

**I was wondering if you could explain the religious**

## **affiliations of the population in DR Congo. What are their main religions?**

It's often said that about 10% of Congolese are Muslim and 90% are Christian. These stark percentages give little sense of the diversity, fluidity and public nature of religious affiliation. Whilst most Muslims are from Sunni traditions and the Catholic Church has a large, prominent role in civil society, there are also many Protestant churches, congregations from both classic and new Pentecostal movements, and one of the largest African initiated churches, the Kimbanguist church. Indigenous religions, often focused upon veneration of the ancestors, are also present and active. Some people are affiliated to more than one tradition and change affiliation over time.

## **Your research is about the element of trust in Congolese religious communities during the pandemic. Would you please explain how trust, religion and health are linked to shaping our response to the spread of Covid-19 in Africa?**

Studies of health systems in fragile states with complex and multifaceted insecurities, like DRC, have identified building trust as a necessary component in the delivery of good health. A lack of trust may be manifest in several ways, including health care being offered in ways that do not account for cultural or religious norms. Over half the health care in DRC is provided by faith-based organisations who generally have great social capital and trust. But not all religious traditions are represented in this delivery. Indeed, some communities will preach faith-healing and divine protection by prayer only. During the Ebola outbreaks there was significant difference in the way in which religious communities responded to protective measures and the same has been true of Covid-19. The project is attempting to identify 1) relations between faith-based health delivery and communities where trust is strong and to build on that in public health messaging around Covid-19. 2) relations of mistrust to understand the cultural



and religious norms that are operating so that public health messages can be communicated more effectively.

**In what ways could health professionals and faith specialists or authorities collaborate to tackle health inequalities?**

As mentioned above, there already is considerable collaboration in some areas. However, there is important work to be done to recognise the public and diverse nature of religious affiliation as part of the health landscape and therefore an important element in building trust in public health measures. There is also a need for understanding of and engagement with all faith groups. We hope the project will provide the knowledge able to train and mobilise the large volunteer force in faith groups (women's networks, youth choirs etc. etc.) who will spread public health messages in an engaging and sensitive way.

The research team in Congo, under the leadership of Dr Yossa Way, is currently collecting primary data. Once this is done, they will make an assessment of exactly how this collaboration might be furthered.

**As you said Christianity and Islam are two popular religions in DRC. It would be interesting to know if the experience of the Ebola outbreak led to greater integration between the communities of the followers of the Abrahamic religions, or has it exacerbated the disagreements?**

Yes, it would be very interesting to know – but unfortunately, I don't think there's any data on this. In our current research we may get some idea of how relationships have changed. Certainly, it's relatively common for civic-minded religious leaders to work together. We see this in Acholiland in Uganda. In 2015 I was able to speak with the Acholi religious leaders for peace. There are similar groups of religious leaders emerging in Congo in response to armed conflict and I'm hoping to learn their make-up and how far

they have responded to epidemics.

*Emma Wild-Wood is senior lecturer in African Christianity and African Indigenous Religions in the School of Divinity. Previously she taught in Cambridge, Uganda and DR Congo. In this project she and other colleagues at the University of Edinburgh are working closely with Drs Amuda Baba, Sadiki Kangamina and Yossa Way of the Anglican University of Congo, Bunia, Ituri.*

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## **Women, midwifery and obstetrics during Covid-19, by Lyndsay Mann**

My ongoing project is called *Women, Midwifery and Obstetrics: Embodied Knowledge, Institutional Practices, and Shared Experience*. This research examines the tensions between embodied, subjective knowledge and scientific, objective information in the context of women-focused institutional healthcare in Scotland using artists' filmmaking methodologies. The work explores themes of awkwardness, authority and the body, relationships between women working together in institutional contexts, and the embodied experience of recognition. This project was started with support from Creative Scotland's Open Project Funding.

The project began in 2019 with New Mothers' Assembly, a series of interdisciplinary workshops I devised for first-time, new mothers. Weekly sessions took place at the Royal College of Surgeons of Edinburgh, and invited new mothers to reflect on their recent experiences of pregnancy and birth in response to historical midwifery and obstetric artefacts from the museum's

collection. Objects became conduits for deeply personal yet collaborative interactions. At this time, I was also beginning to contact women midwives and obstetricians to find out more about their experiences of working in a women-led, women-centred institutional environment. Similarities of responses across all my interactions allowed me to trace a pattern articulating forms of embodied knowledge shared between women, (patients, midwives, and obstetricians) outside of institutional training and practices. Women described some of the most impactful moments of their pregnancy and birth experiences, when they felt seen and heard, resulting from relatable personal anecdotes shared by their healthcare professionals. Fiona Denison, Professor of Translational Obstetrics and Director of the Edinburgh Tommy's Centre, then introduced me to the Midwifery Research Network for NHS Lothian. Through these meetings, the need became clear for me to create workshops, drawing from New Mothers' Assembly, with midwives and obstetricians who have personally experienced pregnancy and birth to discuss contemporary healthcare practices in the context of museum archive and collection materials.

In my work I examine relations between voice, uncertainty, and authority. I develop vocabularies and contexts for sharing personal experiences in relation to institutional histories. Voice is at the core of my work – as a research topic, as an embodied material, and as a set of processes for making. Processes of voice for making include techniques of recording, editing and speaking voice, as well as devising contexts to harness particular forms of voice, such as creating intimate or visceral environments for conversation.

My PhD research in Art was co-supervised in Cognitive Philosophy by Prof Andy Clark. Titled 'Voicing Uncertainty' (2017), it examines ways that perceptions of our voice and of being heard shape our experiences, expectations and capabilities. My investigations through theory and practice

explored the capacity of embodied knowledge to challenge established modes of address and the dominant hierarchies of knowledge and authority they sustain and reinforce.

In developing my work, I often speak with people across disciplines that I perceive as tangentially if not directly related to my research. These sometimes tenuous connections offer ways to rethink or reframe a subject, and the potential to generate new approaches and collaborations on a theme. In so far as knowledge is produced within an historical context of hierarchies that have been assigned values, my interest as an outsider is how outcomes and findings are produced. Which actions, materials, beliefs, equipment, and coincidences bring about a set of perspectives and behaviours that come to be accepted and attributed to a discipline or subject within it, that becomes established knowledge?

Maternal healthcare is an area of institutional practice in which more and more women are the voices of authority, in which many researchers and clinicians have embodied experience of their subject specialism. What differences in forms of engagement and interaction are produced in this workplace environment? Do forms of shared physicality and experience generate alternate forms of communication between colleagues in institutional contexts? Can and do women-led institutional practices move away from harmful patient or colleague perceptions of not being heard, which could be linked to the understanding of authority?

Science and technology are arguably the last collective, trusted voices of authority. The contexts of Women, Midwifery and Obstetrics uniquely address my interests of voice, uncertainty, and authority. The discourse has been heightened by the coronavirus outbreak, and this research has now been re-imagined in response. Between January and March 2021, I am recording a series of one-to-one conversations (online or via phone) with women midwives and obstetricians who have personally experienced pregnancy and birth, and who are

working in maternal healthcare during the pandemic. This component of the project titled, Women, Midwifery and Obstetrics during Covid-19, recently received PRA and RKEI Award funding.

Scholarship on the 'epistemically transformative experience' (Paul, 2013) of pregnancy and birth in relation to healthcare professionals has focused on: the significance of personal connections between patients and their maternity specialists; the complexity of midwives' own maternity experiences in relation to their professional knowledge. (Patterson et al, 2018; Church, 2014; Pezaro, 2018). This project brings together the experiences of women specialists from midwifery and obstetrics for the first time to examine the challenges and needs of recognition between patients and their healthcare providers, additionally contextualised by Covid-19.

Conversations with midwives and obstetricians will explore potential differences of communication between patient and healthcare professionals with shared embodied experiences, and the shifting ground of affinity and disconnection due to Covid-19 practices. It is expected that gathered data will also capture aspects of categorisation relating to 'increased risk' and BAME experiences during the pandemic, and the wider social and political factors implicated in these categorisations. Data and findings from these conversations will contribute to the development of new artworks and a new artist's film, as well as new collaborations with researchers across disciplines at the University.

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*Dr Lyndsay Mann is a research-based, interdisciplinary artist with an expanded performance and moving image practice. She is an ECR and Lecturer in Fine Art in the School of Art at ECA.*

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## **Households, bubbles and hugging grandparents: caring and lockdown rules during COVID-19, by Jackie Gulland**

When the full lockdown to tackle the spread of Coronavirus began in March 2020, mountains of legislation and guidance were published to coerce or encourage people to stay at home. I followed the daily updates closely to try and understand what the rules meant and what the implications might be for families with caring responsibilities. I was struck early on by the use of the term 'households' as the key element of discourse in the guidance. I wondered how this worked for families and particularly for women who rely on networks of care in normal times and for whom the household may not be a safe, secure or sufficient space.

As the pandemic progressed the rules changed, allowing some people to form 'bubbles' with other households, extending their opportunities for social mixing. As a socio-legal scholar, feminist, lecturer in social work and informal carer I wanted to explore the meanings of the terms 'households' and 'bubbles' in the rules and what this meant for gendered caring roles and for inequalities. My article *Households, bubbles and hugging grandparents: Caring and lockdown rules during COVID-19* ([springer.com](https://www.springer.com)) is the result of that thinking.

In the article I explore the legislation under lockdown in the UK (March-October 2020) and the implications for women's gendered caring roles. The regulations and guidance assumed that households are separate units and ignore the interdependencies which exist between households and between individuals and wider society. The continuing focus in the lockdown regulations has been on households as autonomous, safe, adequate and secure. This overlooks the interdependency of human life, gendered aspects of caring and the inequalities of housing and living conditions, highlighted by feminist scholarship. In the paper I show that a feminist analysis of the lockdown rules exposes neo-liberal assumptions about the family household as autonomous and sufficient for the provision of reproductive labour. Feminists have long noted that reproductive labour has been, and continues to be, heavily gendered, with women continuing to carry out the bulk of childcare, housework and adult care. Feminist and disability scholars question neo-liberal ideas about autonomy and emphasise the interdependency of human life. A feminist 'ethics of care' recognises this interdependency and that care is fundamentally relational. In the paper I show how the failure by policymakers to take account of this interdependency has made lockdown more difficult for carers and those in receipt of care. This burden has fallen on women and on low paid, working class and black and minority ethnic women in particular.

The article emphasises the unequal impact of COVID-19, with growing evidence that the greatest health impacts of COVID-19 have been on those in the poorest areas of the country, particularly on black and minority ethnic communities and that there are clear relationships between existing structural health inequalities and the effects of the virus. Evidence from disability organisations, older people's groups and carers' organisations shows that life has been particularly difficult under lockdown. Women have been particularly badly affected by the social consequences of lockdown across a range of issues.

The article outlines the main legal and regulatory framework of lockdown in the four jurisdictions of England, Scotland, Wales and Northern Ireland and how those changed between March and September 2020. Few people probably read the actual legislation but the article notes that language is important and that the use of terms like 'household' and 'care' in both the legislation and the guidance has important symbolic effects, even where regulations are not strictly enforced.

Further examination of these concepts from a feminist perspective helps to reveal the underlying assumptions in the lockdown regulations. The idea of 'household' implies that homes are safe, secure and that there is sufficient space for everyone to isolate together. The idea of the household also assumed that small groups of people or single people could exist in isolation from other households. The exceptions allowing people to leave their homes during peak lockdown were very narrow, with the priorities being work, healthcare, essential shopping, exercise and supporting others who were defined as 'vulnerable'. As the regulations changed over the summer the concepts of 'extended households' or 'bubbles' were introduced to allow some households to mix more often. While these undoubtedly helped some people, particularly those living on their own, the concept of the bubble did not solve the problem of care needs or social isolation for many



parents, older people, disabled people or carers.

I conclude the article with a final reflection on my own position as an informal carer and how the lockdown affected my and my relative's position.

I started writing the article in August 2020 and it was published in November. Since then there have been further lockdowns across the UK and a whole new concept of the 'Christmas Bubble' as we approach the holiday period. The article does not address these new rules but the issues remain. The evidence of the unequal effects of the virus and its social consequences has become even stronger. Let us hope that the virus itself will diminish in its effects but the underlying social inequalities will remain unless there is clear government action to tackle inequality. My own research now turns to thinking about how to better understand and recognise networks of care and inequality and in particular how these affect older women.

*Jackie Gulland is a Lecturer in Social Work in the School of Social and Political Science. Her work is inter-disciplinary and crosses the fields of social policy, sociology, social work, history and law. Her research concerns disability, older people, caring, gender and how people negotiate their rights within the welfare state. Her recent book Gender, work and social control: a century of disability benefits (Palgrave Macmillan 2019), was awarded the Social Policy Association's Richard Titmuss book prize for 2020.*